Navigating the complexities of Acquired Brain Injury: Theorising everyday activities in identity (re)construction

Thesis

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Abstract

This thesis explores the (re)construction of identity after acquired brain injury (ABI). Within this thesis I draw meaning from the every-day experiences of six male ABI survivors and critically investigate their identity (re)construction after their ABI. As well as demonstrating identity (re)construction after ABI, the experiences of the participants have allowed me to investigate neurological rehabilitation after ABI from the perspective of ABI survivors. I seek to achieve a greater understanding of the identities of the participants through enlisting the explanatory qualities of contemporary social theory emphasising the fluidity of identity. As I am a brain injury survivor as well as the researcher in the study, this thesis also explores my experiences of rehabilitation following ABI, as well as my impact on the study. This thesis suggests that rehabilitation after ABI is often a continual process that extends beyond the formal, medically prescribed period. It is suggested further that identity after ABI is often (re)constructed in an unpredictable way; a way that emphasises the importance of reciprocal support and the uncertainty of future life.

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Chapter 1 Introduction

This thesis is concerned with identity (re)construction following acquired brain injury (ABI). The inspiration behind this thesis came from my own personal experience of sustaining a traumatic brain injury (a common form of acquired brain injury) in 2003.This thesis uses the experiences of six males who sustained ABI between the ages of 18-30 to critically explore how their identity has been (re)constructed following ABI. An exploration of the (re)construction of the participants' identity following ABI has also enabled a critical interrogation of the process of neurological rehabilitation through the lens of ABI survivors. In addition I explore my own experiences of identity (re)construction following ABI with a particular focus on how these experiences have impacted on this study. This thesis uses critical social scientific theory as a lens through which to view the process of identity (re)construction following ABI.

In seeking to understand the identity (re)construction process after ABI, this thesis explores dis/ability, difference and the process of research itself. In widening my analytical lens to promote a critical social scientific understanding of identity (re)construction following ABI, I seek to add a further dimension to research concerning medical 'conditions' such as brain injury. Therefore this thesis navigates across and between the medical and social sciences. In striving to understand ABI from a social scientific perspective, this thesis seeks

to be truly nomadic and resists static categorisation to encourage further dialogue across and between the stark borders between the medical and social sciences. The introduction of interdisciplinarity into conversations regarding phenomena such as brain injury enables cross-fertilisation between topics such as medicine, rehabilitation, psychology, disability studies, sociology and research method/ology to name but a few. This pluralistic approach allows a far more detailed and sophisticated approach to the study of ABI. I seek to draw from each of these disciplines to reach towards a more wholesome understanding of ABI. It has been stated that an interdisciplinary approach enables a more sophisticated engagement with impairments than a view which seeks to attribute a fixed and single topic to phenomena (Bolt 2006; Goodley 2007, 2011; Meekosha and Shuttleworth 2009; Smith 2010). As I take insight from a number of competing disciplines, there is an inevitable variation in the language used in existing literature. As such, I now turn to an explanation of some of the language used within this thesis.

A note on language

At the heart of this thesis lies the notion that it is the *person* who has sustained ABI, rather than the label 'brain injured person', 'patient' and so on that that should be of concern to service providers, researchers and so on. This notion has had important implications for the language I have used throughout this thesis. I avoid terms such as 'patient', 'service user' or 'client' as these terms seem to

underestimate the complex nature and deny the uniqueness of the person who has sustained ABI. Furthermore this thesis seeks to explore the identity of ABI survivors through a critical, social scientific lens. Critical social scientific theory highlights the complex nature of identity (Gibson et al. 2012; Goodley 2013b). It would seem to follow then, that this thesis should aim to understand the complexity of the participants' identity rather than defining ABI survivors in terms of their medical 'deficiency'. I believe that use of words such as 'patient', 'service user' and 'client' only serve to reinforce the identification of ABI survivors in terms of their medical 'deficiency'. However, largely due to the universality of the word 'patient' in medical discourses, where unavoidable I reluctantly employ its use.

In addition, throughout this thesis I use the phrase 'person who has *sustained* ABI' rather than 'person who has *suffered* ABI' as the term 'suffer' (and its derivatives) imply an overly melancholic conception of ABI and an unproblematised, causal relationship between ABI and suffering. I also use the term 'brain injury survivor' as this is the phrase preferred in the vast majority of literature which seeks to explore ABI from a personal perspective (Lorenz 2010; Sherry 2006). However, I recognise that the language used to talk of disability, ABI and so on is always in contestation and never static (Sherry 2006). Within this thesis I have used the terminology that was preferable for my participants and language that recent, similar studies were using. I

now wish to discuss the language used to refer to impairment(s) in this thesis.

Within the limited literature which explores ABI from a long-term perspective, there are examples of ABI being termed as an impairment in itself (Sherry 2006) as well as a cause of impairments (Lorenz 2010). Within this thesis, I prefer to view ABI as something which can cause various impairments rather than it being an impairment in itself. After reflecting on the different ways impairment following ABI had been referred to, I concluded that conceptualising ABI as an impairment in itself did not seem to correspond with the way I wanted to frame ABI in my study. Being a person who has many resultant difficulties following ABI, I felt it would be better to refer to these 'difficulties' (difficulty mobilising, talking, remembering etc.) as impairments rather than the ABI itself. Moreover, after being involved in the ABI support group for some time I noticed that both ABI survivors and people involved in their care seemed to refer to their impairments as their difficulty in walking, talking, remembering things and so on rather than the ABI being the impairment itself. Furthermore, referring to ABI as impairment in itself seems to reify the melancholic 'tragic' discourse surrounding ABI which dominates much literature (Gelech and Dejardins 2011; Medved and Brockmeier 2008). It is for these reasons that I made the decision not to refer to the participants' ABI as their impairment.

When referring to the identity of brain injury survivors, I use the term (re)construction. There have been examples of research which highlight the way identity after ABI is wholly transformed (Nochi 1998). Within this research, the process of reconstructing a wholly new identity is important with the old identity being referred to as 'the lost self'. In opposition to this there are examples of research which seek to emphasize the post-injury experience through notions of stability and moral growth (Gelech and Dejardins 2011). I use the term (re)construction throughout the thesis to acknowledge the presence of this ongoing discontinuity between the ways in which identity has been conceptualised after ABI. In the following section I seek to move away from these semantic debates regarding ABI and provide an introduction to how my research is situated within existing literature regarding ABI.

Situating the research within existing ABI literature

In the discussions regarding the clinical literature on ABI later in this chapter and the discussions regarding ABI and disability identity, it is clear that studies that seek to examine ABI or indeed neurological rehabilitation from a critical, social scientific perspective are rare (Gibson and Teachman 2012). Furthermore, studies which seek to represent experiences of ABI survivors are also rare (Lorenz 2010; Sherry 2006; Stewart 2014). A unique aspect of my study is evident in the way I conduct a critical review of both rehabilitation after ABI

and the identity of ABI survivors using contemporary theoretical resources to underpin my view.

Due to my experience of ABI, I am able to add further insights on discussions regarding ABI. Before I sustained my ABI in 2003, I was a trainee physiotherapist. I am therefore able to examine ABI and neurological rehabilitation after ABI from three distinct perspectives. I am a person who is familiar with debates regarding ABI and neurological rehabilitation from the viewpoint of the service provider, the recipient of services and also a researcher. Therefore my opinions cannot be said to be those provided by a service provider, a person who has experienced ABI or a critical social scientist in isolation. The conclusions I am able to draw from this study are gained from my involvement in all three of these arenas. Each of these three strands of my subjectivity play an important role in any assertions I am able to make. This renders a thorough investigation of my own role in the research essential as well as a discussion regarding some of the ways I may have affected the data. I introduce some of the method/ological debates that this thesis provokes later in the chapter. However for now, I turn to a deeper exploration of contemporary social thought in terms of the impact that it seems to be having on disability research.

Critical social scientific theory and disability research

In my thesis I seek to employ critical social scientific theory and use it as a lens through which to view both the identity of ABI survivors and neurological rehabilitation after ABI. Disability has been said to illuminate and put into practice social theory which contribute to the contemporary understanding of disability (Goodley et al. 2012).

Through an engagement with critical social scientific theory, I have become informed with how the work of critical theorists Giles Deleuze and Felix Guattari (1987/2004) and Rosi Braidotti (Braidotti 1991; 2003; 2006; 2011a; 2011b; 2013) may provide a prism through which to view the identity of ABI survivors. The use of the work of Deleuze and Guattari and that of Braidotti has been used as exploratory frameworks for research connected with other impairment labels before. The work of Deleuze and Guattari (1987/2004) is relevant to my study in the way that rehabilitation can be thought of as a non-linear intervention which thrives upon the uncertain potential of the future as it unfolds. I draw from the work of Braidotti (1991; 2003; 2006; 2011a; 2011b; 2013) alongside that of Deleuze and Guattari, as this work compliments and extends that of Deleuze and Guattari in significant and relevant ways. For example, Braidotti's work calls for an affirmative way of conceptualising disability, which celebrates difference and diversity. Furthermore, in recent work (2013) Braidotti draws attention to the closing gap between human

life and non-living objects. This extends Deleuze and Guattari's rejection of such binaries and contextualises their thinking within contemporary social life. As well as being more explicit in her call for an affirmative way of conceptualising disabled people's lives, Braidotti draws close attention to the way all humans interact with the world around them. Therefore the work of these theorists both complements each other and is relevant to an exploration of the identity of ABI survivors. As I became familiar with the recent literature concerning ABI and neurological rehabilitation, I realised that there was a suitable gap in the literature for the incorporation of critical thought. In addition, the work of others in research concerning disability seemed to be incorporating critical theory for example: (Gibson 2006; Gibson and Teachman 2012; Gibson et al. 2012; Goodley et al. 2012; Goodley 2013a; Goodley 2013b; Shildrick 2012). Moreover, it has been noted that 'never has critical disability studies been more necessary' (Goodley 2013a: 74). Thus following Goodley, I critically explore the finer details of the way such theory has guided my project in the next chapter. However, the absence of absolute 'truths', together with the importance of questioning dominant trains of thought were particularly important in the aims of this thesis.

The absence of absolute 'truths'

It has been observed that an exploration of ABI is often concerned with highlighting deficits amongst ABI survivors (Gelech and Dejardins 2011; Medved and Brockmeier 2008; Mills 2011; Sherry 2006). Much research seeks to investigate how ABI can be avoided, or how life can be lived despite the acquisition of various impairments that result from ABI. Without wanting to downplay the importance of such research, I believe there remains a space for research which seeks to depart from the universally melancholic depiction of ABI. This thesis is enacted with the aim of contributing to the filling of such a space. Furthermore, the practice of relying on absolute 'truths' is something that has been said to be thoroughly ingrained in research and practice regarding rehabilitation (Gibson 2012; Gibson and Teachman 2012). Engaging with critical social theory will enable me to restrict the influence of such 'truths' and approach this research without a preconceived impression of what subject position(s) the participants would occupy in their lives (Danielli and Woodhams 2005; Goodley 2007; Mercieca and Mercieca 2010; Mercieca 2011).

The importance of questions

In opening up brain injury /rehabilitation to a plethora of divergent, and at times, critical perspectives, this thesis is primarily concerned with asking questions of assumed practices, rather than providing the

answers to such questions. This is a theoretical approach to the researching of disability and practices involving disabled people which is being increasingly advocated (Shilrick 2012). It has been stated that a contemporary approach to the study of disability '... provides a space... where we grapple with the hidden dangers of ideology' (Goodley 2013a: 77). Following Gibson (2012) rehabilitation is an institutional practice which relies on such ideology, and as such I consider it an ideal practice on which to base a contemporary study of disability.

Although I aim to achieve a pluralistic approach to the study of ABI, the medical aspects of brain injury and neurological rehabilitation cannot be ignored. As such I briefly navigate some of the debates that are to be found in more traditional approaches to rehabilitation in this introductory chapter. This section is intended to 'set the scene' for the thesis by exploring ABI and ABI rehabilitation from a traditional and medical perspective. In the following chapter, I engage with more diverse literature concerning disability and ABI and as such I seek to expand the debate regarding brain injury. Within these opening two chapters I expose the topics of ABI and ABI rehabilitation to concepts drawn from psychology, disability studies, sociology and research method/ology as well as those drawn from medicine and rehabilitation. This interdisciplinary approach permits a wider and more sophisticated discussion regarding ABI and seeks to ask questions of a dominant social practice (rehabilitation) and as a result

would seem to align with contemporary studies of disability. The cross fertilisation of medical and social scientific ideas allows a complex discussion of 'disability identity'. Within this debate lie notions such as the role of embodiment and identity construction. This thesis also seeks to investigate complex issues such as the way power is used (Tremain 2005), the way institutions operate (Goodley 2013a) and the role of the actions of others within disabled people's social worlds, such as those which constitute psycho-emotional disablism (Reeve 2002, 2006; Watermeyer and Swartz 2008). These issues are discussed in the way that they contribute to an understanding of the identity (re)construction of the participants.

Following the above assertions, within the thesis I seek to explore the complicated identities of my participants, and in doing so enable a discussion of ABI as more than simply a medical issue. The concept of 'disability identity' incorporating notions such as psycho-emotional disablism is explored in more detail both theoretically in the literature review, and also in terms of the impact this has on the participants' lives in the data chapters and the discussion which follows. Both the way my participants make sense of their experiences of life together with how they feel they are perceived by others, forms a vital part of this research. This thesis investigates the day-to-day details of the lives of the participants and in so doing provides vital glimpses into ways in which the participants feel their brain injury may have impacted upon their overall life journey. This thesis also allows a

consideration of how those in wider society frame ABI survivors. This includes an examination of the way people position the participants according to the nature of their specific impairments. For example, and following similar cross-impairment work, it will be theoretically important to see if a contrast is evident when observing the difference between the ways the participants with visible impairment(s) are treated when compared with the way their peers with invisible impairment(s) (Dale-Stone 2005; Reeve 2002, 2006).

It appears that largely due to the acquisition of various impairments ABI is often taken for granted that it is 'real'; it may seem ridiculous to argue against this 'fact'. However, contemporary research which seeks to explore the lives of disabled people seems to be moving toward an approach which does not accept taken for granted 'facts' but instead exposes these 'facts' to a thorough and critical examination (Shildrick 2012; Goodley 2011).

Critical thought and the practice of rejection of absolute 'truths' and the importance of questions has also influenced the way I have approached this project method/ogically as well as theoretically. Thus the importance of rejecting taken for granted 'truths' and questioning dominant practices is discussed above in relation to how this study is guided theoretically by a critical framework. For example, rejecting taken for granted assumptions regarding ABI survivors seems to

refute the centrality of impairment in the identity of disabled people (including researchers) and emphasis the situation specific and fluid nature of identity. This seems to be oppositional to the existence of a segregated and impenetrable community of ABI survivors. This may have important implications for my study, not least in a consideration of my influence as an ABI survivor.

Following this, in the next section I seek to introduce some of the important method/ological issues within my project. Firstly I introduce some debates surrounding the method I use. Following this I introduce some of the issues regarding my own position in the project and explore some of the ways that I have impacted on the project.

An introduction to method/ological considerations

Due to the inherent links between the method and methodology (Goodley et al. 2004; Letherby 2002; Sikes 2004) of research projects, and following Goodley et al. (2004), it seems to make more sense for me to talk of the method/ology of the project rather than the methods and the methodology of the research in isolation. My choice of method was undoubtedly guided by the ontological and epistemological issues that comprise my opinions on the value of research. Put simply, my choice of method is inevitably influenced by my theoretical beliefs.

In the lead up to the research project, I was most concerned with coming to terms with the strategies that I could employ to capture the complexity of my participants' lives as richly as possible. I realised that this would help me in my quest to provide comprehensive answers to my research questions. This thesis emanates from the realisation that the existing literature largely fails to address the long-term social as well as the short-term medical needs of people who sustain ABI (Abelson-Mitchell and Watkins 2006; Burton and Gibbon 2005; Conneelley 2002; Grant et al. 2006; Lewinter and Mikkelson 1995; Lorenz 2010; Portillo et al. 2009; Sherry 2006). It has been noted that personal experiences of key life events such as sustaining an ABI are important, as they produce a detailed and an embodied, fleshy example of the negotiation of these events and how they may alter one's life (Smith and Sparkes 2011). Furthermore, it has been commonly stated that humans are essentially storytelling beings and we all have a story to tell (Smith and Sparkes 2008). Narratives bring to light individual life journeys. Narratives encompass a whole myriad of 'truths' that explain the workings of society. In analysing and re-presenting narrative accounts, the 'true' workings of society are presented. Crucially narratives offer insight into how these workings have impacted on personhood at an individual level. Narrative accounts provide a perfect light through which to view wider social issues (Riessman 2008). This led me to a consideration that gaining narratives of ABI survivors would be the most appropriate choice of method. Indeed, the process of gathering

individual stories to explore the workings of dominant social processes and enacting a thorough investigation of the juncture between personal accounts and wider social issues was deemed essential following the work of C. Wright Mills (1959/2000).

Furthermore much contemporary research investigates 'medical' phenomena such as brain injury from a service provider standpoint (Gill 2012). In so doing, such research fails to document the personal experiences of those who have sustained a brain injury. It can be argued therefore, that this research ignores the impact that wider social issues have upon individual biographies; upon individual life-journeys (Sparkes 2000; Ettore 2005; Dumatricia 2010). Representations of personal experiences represents a powerful and often unparalleled way of impacting upon inherent beliefs in society (Barrow 2008; Dumatricia 2010; Goodley et al. 2004; Simpson 2010; Smith and Sparkes 2008; Smith and Sparkes 2011). As Goodley et al. (2004) assert, there is often considerable value within the bounds of life experiences:

> 'Researching life stories offers opportunities for drawing on our own and others' narratives in ways that can illuminate key theoretical, policy and practice considerations'. (Goodley et al. 2004: 167)

Following my decision to interview ABI survivors, I had to decide upon a framework in which to conduct my study. As previously

discussed, my engagement with critical social theory was hugely influential in such a choice.

Much disability research has been termed 'emancipatory' (Barnes 2003; 2008; Stone and Priestley 1996). I state my preference for not wanting to enact my research according to 'emancipatory' frameworks. Rather than conducting my research within the parameters of taken for granted assumptions concerning ABI survivors I wanted my project to retain the ability to grow and develop without having to correspond to a pre-determined set of principles (Mercieca and Mercieca 2010; Mercieca 2011). The word 'emancipation' implies that I have the ability and power to stimulate an acquisition of rights for my participants (Mercieca and Mercieca 2010) and I have no such ability or power. I think the propensity of the study to stimulate any kind of social change is not my responsibility in this research. Having said this, by drawing attention to the lives of ABI survivors, maybe society will consider the lives of people who have sustained ABI to a greater degree in the future (Lawthom and Goodley 2005).

Following these assertions, I made the choice to conduct semi-structured interviews with six fellow ABI survivors. However, there is no doubt that my choice of method was inevitably bound up with my theoretical assumptions (Goodley et al. 2004). I introduce some of

these below paying particular attention to my role in the research production.

The inspiration behind this thesis is my experience of sustaining a traumatic brain injury in 2003. As such, I consider it important to outline some of my own personal biographical experiences of living life after brain injury. I consider this to be an important addition to this thesis for a number of reasons.

Having experienced ABI hand being and being a person who is in the process of (re)constructing identity I can claim to be carrying out this research in an epistemologically privileged position (Letherby 2002). In other words, being able to turn the analytical lens around and critically examine ABI from an ABI survivors' perspective seems to make the assertions I am able to make in the conclusion more relevant as they apply to my own life as well as those of the participants. Additionally, before my accident I completed two years of a three-year physiotherapy degree, and was able to become fairly familiar with the process of neurological rehabilitation. This allows me to view the process of neurological rehabilitation through a third analytical lens (that of a clinician) in addition to that of an ABI survivor and of a researcher. This serves me well both in providing insight into the life of a brain injured person and in achieving a wholly critical interrogation of the process of rehabilitation.

In including my biographical details, this thesis makes explicit the link between personal and public issues (Wright-Mills 1959/2000). It has been noted by Kaufman (2012) that when personal experiences or stories are shared within qualitative research, a space is created for both the storyteller and the listener to connect and grow together, so that each may draw inspiration in their future which is continually 'unfolding' (Kaufman 2012: 16).

Being a person who has sustained an acquired brain injury has had important implications for the way that participants view me as a researcher. This may well have had an important impact on the data I gathered. The positive aspects of participants knowing that I have sustained a brain injury myself include issues related to empathy. Ellingson (1998) emphasises the connections that can be made with research participants when the researcher shares similar experiences. These connections were evident in much of the data in the interview stage of the research, where my participants used phrases such as "you know yourself", "as you know" and so on. Investing time in forming relationships prior to the interviews may well have resulted in the participants trusting and respecting me more than they otherwise would have. It would seem sensible to suggest that this trust may lead to an increase in the richness and depth of the interview data (Hayman et al. 2011; Heliker 2009). As well as providing obvious benefits, my positioning as brain injury survivor

has caused much internal reflection as I have tried to grapple with the complexities of this research.

I have sometimes felt that participants may not have regarded me as a 'professional researcher' (especially in the early stages). Having said this, this may well be due to the way that I tried to create equal and reciprocal relationships with participants, that were more akin to friendships rather than the power laden hierarchical relationships that participants may have been more familiar with. The influence of critical theory upon my project would seem to be important here as it encompasses an acceptance that a person may share (a) specific identity trait(s) with others, thus providing opportunity for experiences to be shared and social bonds to be formed with people who lead very different lives.

Being an ABI survivor has also had implications for the presentation of this thesis. This is apparent in this chapter where I explore my own experiences of ABI. I initially included my own experiences alongside those of my fellow participants in earlier drafts. I reached the decision that perhaps it was best to include a chapter which thoroughly explored my biographical experiences rather than attempting to 'weave' my own experiences with those of the other participants (Cotterill and Letherby 1993). The main reason behind this was that I felt my own views and opinions regarding life after

brain injury and the rehabilitation process were strong and I wanted to ensure that I maximised the opportunity for the experiences of my fellow participants to be represented.

I accept that as with any research that includes an autobiographical element, as author my voice will be most prominent throughout. Having said that, recognising this and noting the importance of my role can only add to analytical rigour of my study, something that is of timely concern to authors who provide a critique of this genre (Atkinson 2006; Delamont 2007). Furthermore, I have thoroughly interrogated and presented my own subjective thoughts about brain injury. Rather than hiding behind these experiences, as if they were something to be ashamed of, I have chosen to embrace them, whilst at the same time fully acknowledging the way that I may shape my data.

Were it not for my experiences of being an ABI survivor, together with my experiences of completing the first two years of a physiotherapy degree, I do not think I would have sufficient interest to want to conduct this study. Whilst I accept I should thoroughly investigate my subjective position and critically examine that position, it seems sensible to use these experiences I have to my advantage rather than trying to be unbiased.

As I more thoroughly discuss throughout the method/ology chapter, it has been argued that the notion of achieving absolute objectivity or ensuring the complete avoidance of any bias whatsoever in social science research is unrealistic (Letherby 2003), not least in the interpretation of 'data' (Letherby 2002). Every person is a unique being and no matter how much objectivity may be striven for, all research is to some extent flavoured by the researchers' experiences and beliefs. Why is the presence of 'bias' always seen as a disadvantage? Life experiences make us who we are, I embrace the uniqueness of my experiences; therefore my research is unashamedly 'biased'.

In drawing some conclusions from this section I am aware of the dangers that a less than thorough appreciation of the method/ological issues in my project may bring to the fore. I believe these dangers to be lessened by not assuming I am overly familiar with ABI. As I discuss throughout this thesis my theoretical framework will guide me in an appreciation of the identity of the participants and will ensure that I do not assume I am inevitably familiar with the issues that my participants will discuss. In-keeping with this notion, I have carried out my research with the knowledge that I am researching people's lives, rather than any impairment(s) or brain injury itself (Goodley and Roets 2008). As well as consideration of my familiarity with the topic of ABI, I have introduced some concerns surrounding the issue

of 'bias' in this thesis. These assertions are more comprehensively explored in the method/ology chapter of the thesis.

In the following section, I provide an interpretation of some of the more common issues that arise in a discussion of ABI and rehabilitation following ABI. I include this discussion as part of the introduction as it seems to enable a realisation of the debates that surround the lives of ABI survivors in short-term rehabilitation, thus laying the foundations for a study of long-term identity (re)construction.

A clinical introduction to acquired brain injury and rehabilitation

In order to appropriately situate my study and to present a comprehensive evidence base for the need for further research, I will briefly outline some important aspects of acquired brain injury including some common approaches to rehabilitation. As is illustrated below, many of the debates surrounding these approaches to rehabilitation are complex and multi-faceted. The focus of my study is the long-term social (re)integration of people who have sustained an acquired brain injury. Therefore, whilst it is important for me to outline some of the main issues within the literature directly related to rehabilitation that are commonly encountered in clinical settings, this introduction is not intended to capture the entire complexity of the

rehabilitation process. Many of the important discussions that seem more relevant to a long-term exploration of ABI such as the impact ABI may have on identity constructions; the efficiency of the rehabilitation process and so on are critically examined in the following chapter. Nonetheless, it is important for me to outline some of the key debates within clinical rehabilitation before moving on to address issues surrounding the long-term social reintegration of people who have sustained an ABI. Before I begin, it is important for me to reiterate the way that within neurological rehabilitation, the person who has sustained the neurological 'injury' is often called 'the patient'. It is with an explanation of what is meant by an acquired brain injury that I begin this appraisal of the clinical literature regarding ABI.

An acquired brain injury (ABI) is an injury at that is caused to the brain after birth. It can take many forms including traumatic brain injury (TBI), Stroke/ cerebrovascular accident (CVA), encephalitis, hypoxic/anoxic brain injury. An acquired brain injury can also be caused by a multitude of other events such as haemorrhage, medical accident and infection to name just a few. It is important to note that ABI only refers to single incident neurological injuries. It does not therefore refer to progressive conditions such as Multiple Sclerosis, Motor Neurone Disease and so on.

It has been stated that traumatic brain injury (TBI) and Stroke are by far the two leading causes of acquired brain injury and are two types of brain injury that are most comprehensively discussed in the existing literature. Much of the information within this clinical review refers to ABI as a singular entity and does not differentiate between different causes of ABI. Furthermore it should be noted that when ABI is sustained, notwithstanding the cause, there are different categories: mild; moderate and severe. This categorisation often dictates the severity of residual impairment(s) and therefore the rehabilitation services provided (Saatman et al. 2008). This is in keeping with the approach advocated in the National Service Framework for Long-Term Conditions (DoH 2005) which focuses on common features of neurological conditions rather than specific pathological diagnoses (Turner-Stokes et al. 2005). This seems to add further support to an approach to my research which does not rely upon the underlying pathological diagnoses, but rather seeks to explore ABI as a single entity. Furthermore within this thesis I do not seek to explore individual pathological diagnoses from the short-term clinical perspective. Nevertheless, it seems sensible for me to spend a little time exploring some common responses to ABI.

People who sustain ABI often (although not always) spend a period of time in acute neurological health care settings such as a hospital. After which more often than not a further period is spent at a neurological rehabilitation facility. The main aim of such facilities is

to restore the person (as far as possible) back to a level of function that was typical to them before the injury.

Amongst the participants, there are ABI survivors who sustained their ABI as a result of Traumatic Brain Injury, Stroke, Brain Tumour and Encephalitis. More detail on my inclusion criteria is provided in the methodology chapter. However, at this stage it is crucial to reinforce the way that there is a considerable amount of heterogeneity involved in ABI (Fleminger and Ponsford 2005).

At a clinical level it is important to note that an acquired brain injury is a particularly heterogeneous injury. It is commonly noted by clinicians that two brain injuries are never the same and indeed the National Clinical Guidelines following Acquired Brain Injury state that 'not all patients require formal rehabilitation following head injury' (RCP and BSRM 2003: 25). Meanwhile, the same guidelines (RCP and BSRM 2003) also state that even within those are said to have sustained mild brain injury, 'proactive follow up and intervention demonstrably improves outcome' (RCP and BSRM 2003: 25), necessitating that the provision of such rehabilitation is thoroughly analysed to maximise the benefit to ABI survivors.

Within existing literature there are a number of approaches that seek to explore ABI through the use of a short-term clinical lens. This has resulted in much of this literature being carried out by and for people such as medical and allied health professionals (Sherry 2006). It is unsurprising then that the literature regarding ABI is dominated by short-term, clinical discussions rather than long-term responses to ABI. Examples of the dominance of short-term clinical discussions regarding ABI are evident throughout debates regarding rehabilitation after ABI. It has been stated that rehabilitation is an important part of life following ABI (Turner-Stokes et al. 2005). Following this assertion, it seems relevant in that I now review literature relating to rehabilitation after ABI.

There has been some concern aired over how to provide a comprehensive evidence base for various approaches within the rehabilitation setting as rehabilitation following ABI is a particularly complex intervention (Turner-Stokes 2008; Turner-Stokes et al. 2005). This has historically made rehabilitation after ABI a very difficult topic to research (Turner-Stokes et al. 2005).

Despite the complexity inherent in rehabilitation research, it is fairly well agreed that rehabilitation is most effective when it is carried out in multidisciplinary fashion with many different professionals working toward common goals (DoH 2005; RCP 2008).

In 2005, a Cochrane review into the effectiveness of multidisciplinary rehabilitation for ABI in adults of working age was published (Turner-Stokes et al. 2005). It was noted that multidisciplinary rehabilitation was indeed beneficial to persons who had sustained ABI. However, it was also observed that much of the research that exists regarding rehabilitation has been conducted within clinical settings and enacted as randomised controlled trials (RCT's). It has been stated that there are severe ethical restrictions for carrying out such randomised controlled trials to evaluate rehabilitation approaches leading to a dearth of research. These restrictions include the severe ethical considerations when randomising rehabilitation approaches to severely impaired people who require the best intervention possible (Turner-Stokes et al. 2005).

In addition the most recent National Service Framework (NSF) for People with Long-Term Conditions (DoH 2005) recognises both the heterogeneity of ABI and the ethical restrictions involved when researching the lives of ABI survivors. It has been described as a 'new style NSF' (Turner-Stokes 2005: 901) which is intended to place far greater emphasis on long-term health outcomes and individual choice. The creation of this NSF recognises the value of implementing evidence gleaned from a far wider array of research methodologies (Turner-Stokes 2005).

The realisation of the importance of long-term health outcomes and individual choice in clinical healthcare NSF's may result in more health-focussed qualitative research studies being enacted, and could serve to end the dominance of the traditional short-term focused clinical research in the form of randomised controlled trials (RCTs). I now turn toward debates regarding the most effective ways of collaborative working in clinical rehabilitation settings. Much of this literature explores the use of teamwork within rehabilitation after ABI.

Teamwork within Rehabilitation

Although recent research and practice within healthcare has suggested that an approach to rehabilitation which includes a multitude of professions is preferred (DoH 2005; RCP 2008), there is still much debate concerning the most effective way that clinicians are able to work together.

At the heart of neurological rehabilitation is the involvement of the disabled person (Barnes 2003). At the very core of the ethos of rehabilitation therefore, is the involvement of a myriad of different professionals, who work together to achieve unique and individual objectives (Barnes 2003). Teamwork within rehabilitation is

considered to be vital. These teams are made up of many different kinds of health care professionals. The teams often include nurses, medics, speech and language therapists, physiotherapists, occupational therapists, clinical psychologists, social workers and sometimes more. The idea behind this approach is to provide an increased level of cohesion between different professions who 'blur their own roles and work together in an interdisciplinary fashion' (Barnes 2003:iv5) to effectively meet the needs of the individual person.

As a result it has been noted that the services provided for rehabilitation are becoming decided far more by the needs of individual people than by the underlying impairment or pathology (Turner-Stokes 2008). Within this individual provision of services, teamwork has been hailed as the cornerstone of rehabilitation services (Diller 1990). As well as being a difficult topic to research, it has also been suggested that teamwork within existing rehabilitation frameworks is not easy to enact. In addition to being a complicated therapeutic intervention (Suddick and De Souza 2007), teamwork has been described as a 'constantly changing process' (Suddick and De Souza 2007: 684) which as well as having benefits for 'patients', also 'brings multiple challenges, and requires extensive resources, investment and commitment if the team is to work to its optimum' (Suddick and De Souza 2007: 684). Some of the most important aspects of teamwork within neurological rehabilitation which are

often cited as a complication are the complexities that surround communication. Many factors such as the size of team (Molyneux 2001), the frequency of meetings (Molyneux 2001) and confusion regarding the general workings of the team contribute to these problems. In addition, it has been stated that a common cause of this confusion is the 'ambiguous' (Choi and Pak 2006) language used to describe the different types of teamwork.

The process of rehabilitation has simply been referred to as 'multidisciplinary' (Turner-Stokes 2008). However, this is not universally accepted as some have made clear the difference between multi-and inter-disciplinary rehabilitation (Coopman 2001; Suddick and De Souza 2006). For Suddick and De Souza (2006) there is a clear difference between multi-and inter-disciplinary teamwork. They argue that whilst multidisciplinary teamwork implies that multiple rehabilitation professions work in conjunction to produce the best outcome for the 'patient', there is still a tendency 'to work within the confines of their own (professional) knowledge base' (Suddick and De Souza 2006; 73). In contrast, interdisciplinarity has been said to refer to the cooperation of diverse professions which work collaboratively, to achieve specific 'social or handicap - related goals' (Suddick and DeSouza 2006; 73). These goals are far more centred on the needs of the patient rather than subscribing to individual professional 'roles' (Coopman 2001; Davis et al. 1992). This situation is complicated even further as others have highlighted the existence of

multi, inter, and even trans-disciplinary teamwork (Choi and Pak 2006). This confusion over the use of language to describe neurological rehabilitation is unhelpful and an increased understanding of the difference between the different types of teamwork within neurological rehabilitation may stimulate more effective service delivery (Turner-Stokes et al. 2005). Furthermore despite the perceived importance of transgressing disciplinary boundaries to adapt rehabilitation according to individual circumstance, there is an absence of literature highlighting the influence of wider family and societal networks in rehabilitation teams.

Despite the variation in language used to describe teamwork, the cooperation and collaborative working between a number of professional disciplines continues to dominate rehabilitation services in the UK (Turner-Stokes et al. 2005). Various teamwork methods often seem to revolve around the goal (target) setting process. Accordingly I now discuss some the complexities that arise when examining the goal setting process in neurological rehabilitation.

The goal setting process

Throughout medical discourse the aims and objectives of ABI rehabilitation that are set for and by the 'patient' are commonly referred to as goals. I now wish to turn my attention away from

teamwork a little and address the way outcomes are measured in rehabilitation following ABI. Despite the existence of many competing definitions of teamwork within neurological rehabilitation after ABI, what seems to be much clearer with in literature is the fact that goals or targets for neurological rehabilitation play a key role in the recovery process (Davis et al. 1992; Playford et al. 2009; Wade 2009). Moreover, it is accepted that these goals need to be set in conjunction with the person who has sustained ABI (Barnes 2003; Playford et al. 2009; Turner-Stokes et al. 2005).

According to the NSF for long term conditions, the current clinical preference is for a 'person centred approach to rehabilitation' (DoH 2005) and the involvement of individual 'patients' in the goal or target setting process. As well as figuring prominently in the NSF for long term conditions (DoH 2005) this also appears to be an important component of rehabilitation within the National Clinical Guidelines for Stroke (RCP 2008). Furthermore other guidelines which set out how rehabilitation should be conducted, also stress the importance of the involvement of the individual in goal or target setting (RSP and BSRM 2003).

As well as appearing prominently in clinical guidelines relating to ABI rehabilitation, within clinical literature there is also an emphasis on how the setting of goals has been considered paramount to the

rehabilitation process (Playford et al. 2009). The goal setting process in neurological rehabilitation is largely based upon Schut and Stam's (1994) framework. This framework indicated that the goal setting process should be conducted according to a number of factors. They introduced the acronym 'SMART' (specific, measurable, achievable, relevant, time-limited) which was intended to make the goal setting process simpler. As suggested above this is the preferred method by which to set goals in many clinical settings (Playford et al. 2009). However, there is also evidence that suggests there are a number of different interpretations of this acronym (Barnes and Ward 2000; Mastos et al. 2007; Playford et al. 2009).

Despite the usefulness of the 'SMART' acronym (Schut and Stam 1994), it has been observed that there is still much to be researched concerning the goal setting process (Wade 1998). Playford et al. (2000; 2009) agree with this and add that a lack of research into the goal setting process has led to the assumption of many different approaches to goal setting. This is also an issue that is raised within the research carried out and reviewed by Wade (1998; 1999; 2009). Some of these differences can be observed when deciding how these 'patient centred goals' are to be a set. Furthermore considering the heterogeneity of ABI (Fleminger and Ponsford 2005) then it would seem likely that the nature of these goals is going to vary widely between different people. For example, one approach could stem from an ABI survivor who may wish to set goals that address their short-

term, impairment based difficulties following their ABI. However, there could also be ABI survivors who want their goals to be directed towards their long-term social needs. Wade (1998) poses the question of how can these varying goals be effectively measured within existing frameworks?

Within current UK frameworks ABI survivors are commonly provided with rehabilitation services together with those who live with other types of impairment(s) such as those that are chronic/progressive in nature (Turner-Stokes et al. 2005). The success of goal setting has been said to be partly variable depending upon the type of impairment being considered (Playford et al 2000). During a workshop discussion exploring professional perceptions of the goal setting process, it was highlighted that the process of goal setting was far more successful when conducted with patients with chronic/progressive impairments than it was with patients who had sustained a single incident such as ABI (Playford et al. 2000).

Furthermore as well as observing differences between goal setting success according to impairment categories, the variability in the severity of impairments has also been highlighted as playing a huge role in goal setting (Playford et al. 2000). For example, it was observed that the clinical goal setting process (with a focus on short-

term goals) was 'likely to be seen as trivial by the more disabled patient' (Playford et al. 2000: 495).

Although now considered to be a process which is at the very heart of modern rehabilitation, the issue of when to involve 'patients' in the goal setting process was discussed in a recent paper (Dalton et al 2012). It was observed that when individual 'patients' were involved in the goal setting process earlier and to a greater extent, there was an overall increase in the number of goals set. Crucially, this was particularly observed in the setting of more functional goals, which may relate to the resumption of social activities (Dalton et al. 2012). This would seem to concur with the above literature that indicates the goal setting process is important in rehabilitation and should involve the individual as much as possible. This would seem to suggest that ABI survivors should be involved in the goal setting process at an early stage of their rehabilitation. Issues of power relations are most relevant in a discussion of when to involve ABI survivors in the goal setting process. The implications of power relations in identity (re)construction are discussed further in the next chapter.

Regarding the setting of long-term goals it has been stated that goal setting for period of life which is uncertain must be viewed as problematic (Playford et al 2000). Some clinicians have observed that an alternative approach could focus on the incorporation of a person's

long-term life goals into plans for rehabilitation (Sivaraman Nair 2003). Indeed it has been stated that the motivation of a patient largely depends on the concurrency of rehabilitation goals and life goals (Sivaraman Nair 2003). This observation becomes eminently more powerful when we are reminded that the success or failure of the rehabilitation programme largely depends on patient motivation (Dalton et al. 2012; Playford et al. 2000; Turner-Stokes 2008; Sivaraman Nair 2003). However, the literature would appear to indicate that clinicians and ABI survivors find it difficult to set appropriate goals at a time when one's future destiny is undecided. This often results in feelings of fear confusion and worry at not achieving goals (McGrath and Adams 1999).

In an overall appraisal of the importance of goals in rehabilitation it has been suggested that rehabilitation professionals play an important role in the managing of 'patient' expectations and helping the 'patient' to set achievable and realistic goals (Sivaraman Nair 2003). This is important to remember, and indeed included in the widely adopted 'SMART' approach to goal planning. It is apparent however that long-term goals remain extremely difficult to set within this existing framework.

During rehabilitation after ABI, there is also great debate concerning the stage at which rehabilitation services should be provided in the

community rather than in a hospital-based setting. I now examine some literature at the forefront of this debate.

Community versus hospital-based services

I continue the exploration of rehabilitation following acquired brain injury with a presentation of the continuing debate that surrounds community rehabilitation services when compared to such services based in rehabilitation units/ hospitals. As I explore below, it is perhaps within the literature in this area that the true level of heterogeneity in people who require neurological rehabilitation services is fully realised. It has been stated that services have to account for a wide range of neurological deficits, both sudden onset in nature and also progressive (RCP and BSRM 2003). This situation is complicated still further by an acceptance of the above discussion that suggested each neurological deficit manifests itself in different ways, and to different extents.

It has been stated that it is perhaps with the consideration of whether rehabilitation should take place in a hospital or a community setting, that the greatest difference between sudden onset neurological incidents and progressive disorders may well lie (RCP and BSRM 2003). This would seem to follow, as it makes sense that the effect that a period of intense, inpatient rehabilitation can have following

ABI can be very different to the effect rehabilitation can have in life of a person with a progressive disorder such as Multiple Sclerosis. In the case of ABI, the severity of the ABI is crucial in the decision regarding whether community-based or inpatient rehabilitation is provided (RCP and BSRM 2003). Furthermore these guidelines state that patients who make a rapid recovery following the emergency treatment for their injuries may be able to go directly home after a careful medical review and referral onto specialist community rehabilitation services (RCP and BSRM 2003). For people who sustain more serious ABI, there is a widespread acceptance that an initial period in a hospital based neurological rehabilitation unit is the preferred approach (Barnes 2003; Barnes and Radermacher 2001; RCP and BSRM 2003; BSRM 2008). In the vast majority of cases, there is a tendency for 'individuals to be discharged after a few weeks or months from hospital-based rehabilitation units' (Barnes and Radermacher 2001: 44). However, it is concerning the provision of long-term rehabilitation that the debate over whether rehabilitation services should be hospital or community based is primarily located.

There is an understanding that rehabilitation following ABI will continue for some time within the community setting. However, such people are often 'poorly served by inadequate community rehabilitation resources and facilities' (Barnes and Radermacher 2001: 44). For example it was observed by the British Society for Rehabilitation Medicine (BSRM 2008) that community-based

services were unacceptably poor. The lack of medical consultants specialising in rehabilitation medicine was cited as one of the most enduring reasons for this lack of community-based facilities. This is important given the well documented need for rehabilitation to focus not just on medical well-being but also on long-term social factors (Abelson-Mitchell and Watkins 2006; Burton and Gibbon 2005; Conneelley 2002; Grant et al. 2006; Lewinter and Mikkelson 1995; Portillo et al. 2009). Notwithstanding the reasons for lack of long-term community-based services, this lack of services is undoubtedly relevant to a study of long-term rehabilitation after ABI (Abelson-Mitchell and Watkins 2006; Conneelley 2002).

Entangled with debates concerning the location of service provision in long-term rehabilitation after ABI is debate surrounding the length of time that 'recovery' can take. Consequently, I now continue the discussion regarding rehabilitation following ABI with an exploration of some common beliefs concerning the length of time that rehabilitation services should be provided for.

Length of recovery?

Considering the above literature, the question of just how long rehabilitation services should be provided for would seem to be a tricky question to answer. However, I am investigating the

(re)construction of identity amongst ABI survivors which necessitates an investigation of how my participants have (re)integrated into society on longer-term basis. This dictates that the literature discussing the length of time that rehabilitation services should be provided for is a vital body of literature for my study. It has been observed that there are many intertwining aspects of the rehabilitation process that need to be addressed when stating how long rehabilitation should last for (Fleminger and Ponsford 2005).

In general it has been stated that rehabilitation and healthcare more generally are guided by basic societal assumptions concerning what a successful outcome may be (Gibson and Teachman 2012). Gibson and Teachman (2012) continue and assert that as a result, basic societal assumptions concerning rehabilitation remain largely unproblematised and are reflected in much clinical practice. A close engagement with this literature concerning societal assumptions is in the following chapter together with a discussion of how ABI survivors' lives are classified according to a comparison with societal understanding of the rehabilitated body. Importantly however, the assumption of dominant societal practices leaves little room for a thorough exploration of rehabilitative practices directed toward and imagining how things could be otherwise on a long-term basis (Gibson and Teachman 2012).

An example of this lack of imagination in the long-term conceptualisation of ABI rehabilitation can be found in the way that notions of dependence, independence and interdependence are conceptualised in medical (and rehabilitative literature). I feel it particularly important to note the way that in such discourses 'the myriad relationships between persons with disabilities and the machines, tools, persons or animals that assist them are characterised either as dependencies and/or means to achieving independence' (Gibson 2006: 187). For disabled people such notions of dependence lead to unhelpful visions of disability which emphasise passivity and a need for care (Watson et al. 2004).

Notwithstanding debates surrounding dependence, independence and interdependence, ABI has been said to be among the very leading causes of long term of disability in the adult population (Fleminger and Ponsford 2005; Petterson et al. 2002). Although it is fairly well accepted that the vast majority of recovery following ABI occurs in the two years immediately following the injury (Cockburn et al. 2003; Fleminger and Ponsford 2005; Steadman-Par et al.2001; Turner-Stokes 2008), there is also documentation that suggests the existence of an unpredictable and uncertain period of growth, change and progression that can extend far beyond this (Cope, Mayer and Cervelli 2005; Feminger and Ponford 2005; Lorenz 2010; Turner-Stokes et al. 2005) especially concerning those of a younger age (Cope, Mayer and Cervelli 2005; Forsyth 2010). For example, when

concerning the role of employment in identity following ABI, it would be problematic to pre-determine a time-scale considering that no two brain injuries are ever the same (RCP and BSRM 2003).

Consequently, it has been observed that the brain injured patient 'faces an uncertain future' (Fleminger and Ponsford 2005: 1419). Indeed, it was noted that 'it is the injured person who must negotiate a lifelong journey with a brain injury' (Fleminger and Ponsford 2005: 1420). This statement seems to recognise the heterogeneity of a person who may have sustained ABI. The heterogeneity of ABI has been discussed previously in this review with particular reference to discussion of the notion of individual choice and the importance of paying great attention to the views and opinions of individual 'patients' (DoH 2005). It has been stated that long-term studies often seek to represent the opinions of the people that are affected by such policies are important in maximising the efficiency of the neurological rehabilitation process (Turner-Stokes et al. 2005). This is a departure from the type of the empirical data that investigated the clinical aspects of the short-term rehabilitation process (Turner-Stokes et al. 2005). The avocation for and production of more long-term research seems to be encouraging the gathering of evidence which takes into account individual choice and preference. However, deeply embedded within debates regarding the length of time services should be provided for are those surrounding the economic cost of the provision of such services.

The financial costs of rehabilitation undoubtedly demand consideration in any debate regarding the provision of rehabilitation on a long-term basis. It has been stated that in the UK, rehabilitation services have been fairly flexible and adaptable to suit individual 'patient' needs (Turner-Stokes 2007). However, in the current climate of financial constraint there is a pressing need to demonstrate cost efficiency of rehabilitation services (Turner-Stokes 2007). I have explored the debates regarding shortcomings in community rehabilitation service provision above. Given the above cited lack of community rehabilitation services, people who have sustained ABI would appear to be left without rehabilitation services to fulfil their long-term needs. Once again the fact that 'different people require different programmes of rehabilitation and progress at markedly different rates' (Turner-Stokes 2007: 1021) is described as being a key aspect of the rehabilitation process and therefore may well have implications for the way rehabilitation budgets are used (Turner-Stokes 2007).

Due, in part to the inherent lack of criticality in rehabilitation literature (Gibson and Teachman 2012), within this brief introduction to the rehabilitation literature I have sought to highlight areas where critical social scientific theory may provide a way of improving services. Therefore, I am keen to emphasise the way that rehabilitation does indeed benefit those who receive it (such as myself). Also I seek to explore the ways in which a closer

engagement with critical social scientific theory could stimulate service improvement. I now summarise this section by stating some the ways this literature has informed my exploration of identity (re)construction following ABI .

The way rehabilitation literature influences a study into identity (re)construction following ABI

When analysed for an investigation into the effect of long-term rehabilitation services, much of the literature seems to be implying that rehabilitation after ABI is a process that is unique to each person and should as far as possible aim to include the individual person. Within this study I seek to investigate the (re)construction of identity amongst my participants. I conduct an interrogation of the neurological rehabilitation process after ABI through gaining an appreciation of participant experiences. I explore the way participant identities were considered in the rehabilitation process, gather their opinions on where their rehabilitation took place, collect their thoughts regarding the importance of independence following ABI and obtain their views and the length of their rehabilitation. The literature above has been deliberately ordered so that the opinions on the length of recovery appear last. This seems to act as an effective precursor to the literature which is reviewed in the following chapter which analyses social scientific material related to the (re)construction of identity among ABI survivors. However before I

turn my attention to this task, I conclude the introductory chapter by providing an impression of the presentation of this thesis.

Structure of the thesis

Within this introductory chapter I have introduced my research project before discussing the importance of both taken for granted assumptions and the way that contemporary research seems to be providing a critical space for questioning the basis of these assumptions (Goodley 2013a; Goodley 2013b; Shildrick 2012). I continued this introduction by exploring some method/ological debates that come to the fore during this thesis. Towards the end of this introductory chapter, a critical investigation of some common clinical debates is enacted. These issues do not necessarily correspond with the overall tone of the thesis, which seeks to investigate ABI and rehabilitation after ABI from a critical, social scientific perspective. However due to the close ties between debates around ABI, ABI rehabilitation and clinical issues, a review of this body of literature is essential. This literature is intended to highlight the existence of the dominant (clinical) way that ABI is conceptualised. This review is intended to act as a precursor to the literature review regarding the identity of ABI survivors.

Chapter Two follows on from the material presented later in the introductory chapter and is comprised of a review of literature that

pertains to the (re)construction of identity after ABI and therefore the (re)construction of identity among the participants in my study. This includes discussions surrounding the notion of disability identity; the use of power in the lives of those who have sustained a brain injury and indicates how I will draw upon contemporary theoretical resources to enrich my analysis. After reviewing literature regarding the (re)construction of the identity of ABI survivors, two of the three questions that the thesis seeks to answer are proposed.

Chapter Three is a narrative presentation of my own experiences of ABI. This chapter has two main functions. First this chapter situates my perspective on brain injury and some of my experiences which have led me to this project. Second, this chapter provides an exploration of my own experiences of identity (re)construction after ABI which without doubt have influenced the empirical data (chapters 5 and 6) together with the conclusions I am able to reach at the end of this thesis. Within this chapter I seek to contextualise my perspective on ABI by detailing some of my life experiences which have led me to this project.

Chapter Four consists of a critical interrogation of the method/ology of the thesis. A thorough examination of the suitability of the method for this thesis is enacted. Together with this discussion of the suitability of the methods I use, I enter into a critical debate which

teases out some of the more complex methodological considerations that are most pertinent in this thesis. Following Letherby et al. (2012), given my commitment to theorising the subjectivities of both my participants and myself, an introduction to the participants is given in this chapter. In addition, this chapter discusses my decision to volunteer within the support group during data collection and my unique positioning as a brain injured researcher, interrogating the way my previous experiences may have influenced the research. I include a consideration of the centrality of my position as a researcher and some of the ways this may have strengthened or weakened the thesis. This debate directly addresses the final research question which seeks to interrogate my influence on the project. Discussions regarding the method/ology of the thesis are continued in a critical interrogation which proposes the relevance of the use of the analytical technique of 'thematic analysis' when analysing my data. Finally, I provide an account of how the study was enacted including an explanation of how ethical clearance was achieved.

Chapter Five is the first of my 'data chapters'. Within this chapter I seek to provide empirical data which may be used to critically interrogate the viewpoint which suggests that rehabilitation should be enacted as a quest to regain independence. In the above section that is concerned with the reviewing the literature concerning the length of recovery the existing literature seems to question the importance of independence in contemporary society. As such I seek to explore this

further through engaging with the experiences of my participants that are related to notions of dependence, independence and interdependence. As well as being a key component in the (re)construction of identity amongst ABI survivors, the empirical data within this chapter is directly related to the second of my research questions which proposes an investigation of the efficacy of contemporary rehabilitation.

Chapter Six is the last of my data chapters. This chapter seeks to trouble the way that rehabilitation is often regarded as a fixed and bounded activity that only occurs in designated 'rehabilitative' spaces and at set times. This chapter is primarily concerned with providing empirical data to interrogate the process of rehabilitation which is demanded by my second research question. However, in my discussion of the contemporary and future actions of the participants, I inevitably touch upon the issues related to the (re)construction of their identity. Consequently, in this chapter I also contribute data that is related to the first of my research questions.

Chapter Seven is the final chapter of the thesis. Within this chapter I seek to undertake a wider discussion of the both empirical data and the theoretical assertions that comprise the thesis. This chapter allows me to incorporate the empirical evidence that I have gained with the existing literature on the identity of ABI survivors and rehabilitation

after ABI. I state the unique contribution to knowledge that this thesis has made and demonstrate how my thesis has contributed to literature regarding the identity of disabled people and literature regarding the neurological rehabilitation process after ABI. I draw some method/ological conclusions comprising discussion of the methods I used and also my position in the research. Following a discussion of some of the limitations of my study, I conclude the thesis by proposing some areas for future research.

Conclusion

Within this chapter I have laid the foundations for this thesis. I have reviewed literature that is relevant to the short-term clinical aspects of brain injury. This is intended to form a precursor to the material in the following chapter which investigates long-term issues in identity (re)construction. The research method/ology that I have chosen to employ is also critically discussed. A review of literature regarding ABI and rehabilitation with a discussion of the literature which relates to short-term debates within the field can be extended by an emphasis on long-term identity (re)construction. Therefore having laid the foundations for this study, the next chapter seeks to build upon these foundations by reviewing the literature concerning the (re)construction of identity among ABI survivors.

Chapter 2 The existing literature related to the (re)construction of identity of ABI survivors

Introduction

Having reviewed literature that discusses the neurological rehabilitation process after ABI from a clinical perspective in the previous chapter, this chapter addresses the existing literature that is related to the identity of ABI survivors. Within this chapter I discuss this literature as it relates to my study, providing a clear impression of some of the ways that my study adds to the existing literature concerning the identity of ABI survivors. Considering that my study seeks to explore the identity of ABI survivors, much of this literature is directed toward a long-term exploration of ABI survivors/disabled people's lives from a long-term, critical social scientific perspective. This long-term, critical social scientific perspective adds to the body of research concerning ABI and ABI rehabilitation, where research has largely focused on the medical aspects of the neurological rehabilitation process, rather than the way ABI impacts on a person's identity (Sherry 2006).

Within this study I seek to engage with contemporary social scientific theoretical assertions that guide us towards viewing the (human) body as a constantly developing organism which is:

> '... no longer seen as a stable, grounding category that can be taken for granted, but as a discursive construction, which indicates that all sorts of epistemic, ontological and ethical claims must be rethought' (Shildrick 2012: 36).

Considering this assertion, it seems to follow that there is a place for research which explores the diverse nature of the lives of disabled people. Furthermore, such research would investigate the disabled body as 'a discursive construction' rather than a 'stable, taken for granted category'. In order to help me to understand the complex lives of the participants, I will be drawing on a contemporary theoretical approach to critically explore the issues relating to the nature of the participants' identities. I engage with the lives of the participants with the aim of providing an impression of their lives as a 'discursive construction' (Shildrick 2012: 36) which is open to adaptation, rather than conceptualising their bodies as homogenised, stable, brain injured entities.

It has been noted that a brain injured person's rehabilitation does not end upon discharge from in-patient rehabilitation services (Abelson-Mitchell and Watkins 2006; Burton and Gibbon 2005; Conneelley 2002; Grant et al. 2006; Lewinter and Mikkelson 1995; Portillo et al. 2009). Thus this indicates that there is much to be gained from an exploration of the lives of ABI survivors after they are discharged from inpatient services.

A key element in the rehabilitation process is the provision of services that strive towards 'assisting that individual to cope with family, friends, work, and leisure as independently as possible' (Barnes 2003: iv3). This statement implies a commitment to long-term rehabilitation, rather than simply a short-term focus. Despite this, long-term outcomes such as vocational outcomes after ABI are recognised to be poor (RCP and BRSRM 2003) meaning that there is a need for further research in this area.

A sophisticated engagement with the lives of ABI survivors and one which seeks to promote an increased understanding of the identity of brain injury survivors would contribute to filling this gap in research. Within this chapter I explore some of the ways that existing literature can inform a sophisticated engagement with the identities of ABI survivors.

I now turn to a discussion regarding the way previous studies have conceptualised disability as a wholly medicalised and individual or social and group issue. This literature enables me to demonstrate the need for a study which seeks to increase understanding of the complexity of identity of ABI survivors.

A space for a critical social scientific assertions

Historically disability has been seen a problem or deficit that resides in the individual person and was framed as a problem that needs to be

overcome by that individual (Oliver 2004). This was fuelled by the so-called medicalisation of disability, which individualised impairments and caused a great deal of dissatisfaction (Oliver 2004). Disabled people and their organisations, refused to continue to accept being identified according to their various impairments, wishing to end the ubiquitous presence of medical discourses in their lives. As is pointed out by Barnes (2012) a radical departure from the medical conceptualisation of disability was to fuel a whole host of political transformations. In short the focus was to be transferred to the achievement of a fairer and just society which accounted for all people both non-disabled and disabled (Barnes 2012).

In accordance with the medicalisation of disability, research into brain injury is predominantly conducted within the medical arena (Sherry 2006). Such studies are often conducted within clinical settings and appear in journals such as *Brain Injury, The British Medical Journal, Rehabilitation* and *Neurology* amongst others. These clinical research studies are often grounded in the experience of medical professionals such as neurologists, neurosurgeons, psychologists and so on. These research studies are useful and indeed worthwhile in many ways, not least in providing a resource to clinicians who help people with the effects of brain injury.

However, the abundance of these studies together with the lack of investigation into the (re)construction of identity amongst ABI survivors has provided an ideal breeding ground for the growth of the dominant societal belief that brain injury equates to damaged person (Sherry 2006). This may well be due to the uncritical acceptance of ABI being a wholly medical issue. As such, medical accounts have become the dominant discourse in brain injury research and practice. These narratives have been said to frequently draw attention away from individual experience, and as a result close down opportunities for individual growth in homogenising such experiences (Gelech and Dejardins 2011; Richards 2008).

At the same time, an approach which places too much emphasis on the existence of disabled people such as ABI survivors as a tightly bound collective, who do not differ according to impairment factors has also been criticised (Shakespeare 2006). Such a conceptualisation is provided by the social model of disability and a consideration of the role of society in disabled people's lives.

Although the increasing focus upon the role of society in a consideration of disabled people's lives is largely accepted (Barnes 2012), others have stated that critique is necessary in all spheres of life (Salih and Butler 2004). This train of thought would suggest that exchanging one dominant discourse (medicine) for another (socio-

political) in an uncritical way would be a sideways step (Shakespeare 2006; Shildrick 2012). Suggesting that certain perspectives are in some way exempt from being critiqued could be also be seen as counter-productive to the creation of 'new possibilities' (Salih and Butler 2004: 331) especially concerning the lives of disabled people.

In this research I am using an analytical framework which gives credence to the view which suggests that it is worthwhile to explore both the medical aspects of the impairment and the interaction of wider social networks of the participants. By engaging with the lives of ABI survivors, I seek to explore identity after ABI from a fluid and 'nomadic' Braidotti (2011b) perspective. Following Braidotti (2011b) such a perspective dictates that there may well be ample space to integrate social as well as corporeal issues as they interact in unexpected ways to comprise the identity of ABI survivors.

Considering the social model of disability in an exploration of the lives of people who have sustained ABI

The aim of this study is to explore the (re)construction of identity of ABI survivors. Therefore, it is considered relevant to discuss the way identity is (re)constructed in disabled people. One key area of discussion is to what extent disabled people form a cohesive group identity or how much impairment is contextualised into a person's overall identity. Within scholarship that investigates the role of

impairment in people's lives, there is much disagreement as to whether an individual wishes to always identify as disabled and become part of a social 'group', or whether impairment is seen simply as a single facet of identity. Due to the amount of disagreement and discussion surrounding this, it is clear that there is not one simple answer.

One opinion is provided by the Disabled People's Movement (DPM) in the UK, who make a distinct and oppositional divide between impairment and disability (Hughes 2009). This distinction was made largely in response to the exclusion of people with impairments from everyday life and on the definition of impairment as simply a medical issue which refers to the 'functional limitation within the individual caused by physical, mental or sensory impairment' (Disabled People's International 1982). According to this view, any disability which resulted from impairment(s) is wholly differentiated from the impairments themselves. Disability was (re)defined as a purely social construction. Thus, The Union of Physically Impaired against Segregation argued that:

> 'In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society'.' (UPIUS 1976: 3).

Before this time, the publication of issues pertaining to disability were largely restricted to autobiographies depicting tales of triumph and isolated 'success stories' in overcoming woeful circumstances (Barton and Oliver 1997). The documentation of the views of UPIUS was a pivotal turning point in the way that society considered disability and disabled people. Shortly after the publication of UPIUS' thoughts came the birth of the social model of disability (Barton and Oliver 1997).The central premise of the social model was the continuation of the idea which separated impairment and disability as two different phenomena. In short, this invited us to consider that impairment does not necessarily lead to disability, for one may have a particular impairment, but if their needs are met adequately, disability is not an unavoidable consequence of impairment (Barnes and Mercer 2004; Campbell and Oliver 1996; Oliver 1996; Swain, Finkelstein, French and Oliver, 1993; Tregaskis 2004). If disability does indeed ensue then the disability is something which is caused by a society which does not account the needs of people with impairment(s). Therefore according to this framework, the impaired subject (the person who has sustained ABI) becomes disabled by the barriers that society creates in not foreseeing the needs of all people. The establishment of a clear difference between impairment and disability was to provide a pivotal point for all disabled people (including those who had sustained ABI).

However, this polarisation between disability and impairment is not without opposition. The presence of the social model and the polarisation of impairment and disability has created much debate within academic research which seeks to represent the views of disabled people (Barnes 2012; Shakespeare 2006). For example, the strict and inflexible dichotomy at between impairment and disability that the social model promotes is problematic for many, including Tom Shakespeare who in his (2006) text *Disability Rights and Wrongs* offers the view that the social model of disability has 'largely failed to produce good empirical research, because it relies on an overly narrow and flawed conception of disability' (Shakespeare 2006: 9). In this text which was to reinvigorate the contemporary study of disabled people, Shakespeare cites many reasons for the 'failure' of the social model of disability. The way that the social model creates an inflexible polarisation between impairment and disability is one of the more compelling arguments posited. Shakespeare urges research concerning disabled people to further engage with the 'reality' of disability such as issues of pain. Shakespeare believes that future research should give more credence to the embodied and corporeal aspects of disability rather than continuing to emphasise the difference between impairment and disability.

In addition, for Hughes and Paterson (1997) the way that the social model of disability refuses to engage with bodily issues, results in a

situation whereby the social model of disability 'concedes' (Hughes and Paterson 1997: 326) the impaired body to medicine. Within this paper, Hughes and Paterson argue that the issues of disability and impairment are inextricably connected. Crucially, Hughes and Paterson promote a move toward 'not the supercession, but for the expansion of the social model' (Hughes and Paterson 1997: 326). In short they advocate a model of disability that takes into account an embodied notion of disability.

Similarly, Nick Watson (2002) questions the existence of an overall 'disabled identity' and the fact that that the 'category' of disabled person should be 'historically situated, socially composite and seen as part of a multiple identity' (Watson 2002: 513). Meanwhile, in her research carried out within a community leisure centre, Claire Tregaskis (2004) notes that rather than exclusively focusing on the impairment-disability divide, future research may well flourish by engaging with the interface between disabled and nondisabled people. Tregaskis promotes the creation of opportunities which would see:

> '... disabled and non-disabled people coming together on an equal basis to achieve a common goal, [and] a cooperative model of working that may point the way towards a common future based on mutual respect and the equal valuing of difference' (Tregaskis 2004: 3).

Arguably, within much of the existing literature pertaining to disabled people the removal of the causal link between impairment and disability seems to create an all-encompassing disabled identity, thereby emphasising difference between those who are disabled and those who are not. As a direct result of the emphasis of these differences, an oppositional divide between non-disabled and disabled people can be observed. The creation of binary, polarised thinking, particularly concerning disabled people's lives, has been said to over simplify disability and close down possibility for relational interconnection within social networks (Roets and Braidotti 2012). The voracity of this debate surrounding the social model of disability and the separation of impairment and disability means that there is not one simple answer that will satisfy all disabled people or even all people who have sustained ABI. The degree of variation in the views of disabled people towards this matter may well add further weight to the assertion that there is no one all-encompassing 'disabled identity'. In enacting a thorough exploration of the identity of the participants, this study seeks to add to the body of literature that is dedicated to investigating the identity of ABI survivors and disabled people.

Despite discussions regarding the importance of the impairment in the lives of ABI survivors, it would seem sensible to suggest that the period of time immediately after the ABI is important in terms of identity (re)construction. The use of power in rehabilitation settings and the extent to which the bodies and minds of people who have

sustained ABI are considered deficient throughout the rehabilitation process would be important. It would follow then that a study investigating the (re)construction of identity after ABI would benefit from an exploration of how power is used within the rehabilitation process after ABI. I now turn to such an exploration.

Acquired brain injury and power

Discussion of the use of power in the lives of ABI survivors is crucial in any discussion of identity (re)construction. The literature suggests that power is a concept that continually surrounds ABI survivors from when they are in rehabilitation units right through to every-day interactions in society. This suggests that power is a concept that is always at play throughout the (re)construction of identity after ABI. However, some authors have questioned the impact of power relations in identity.

The subject of power and the way that power is used to control people who deviate from the societal definition of 'normal' was the focus of much of the later work of Michael Foucault (1977, 1979, 1980). This work has proved to be hugely influential and Foucault's ideas have been applied to a vast array of disciplines that have shed light on historical through to contemporary social practice (Tremain

2005). The subject of power would then seem to have an important role to play in the (re)construction of the identity of the participants.

Within studies that seek to capture the complexity of how a variety of impairments impact on disabled people's lives, there have been examples of research being carried out which investigate the transmission of power within medical settings (Tremain 2005). This research serves to act as a departure from much 'traditional' research conducted by/with/on disabled people, which sought to redefine disability as a form of social oppression (Oliver 1990). Lately, however, there has been an increasing amount of literature which has cited the fact that disability and medicine are, for better or worse, inextricably and forever married (eg. Corker 1998; Hughes 2009; Hughes and Paterson 1997; Snyder and Mitchell 2001; Shakespeare 2006; Turner 2001; Williams 2001; Zola 1991). This has led to the assertion that 'the repertoires of the sociology of the body are becoming entangled with a whole host of issues that impinge upon disability identity' (Hughes 2009: 400). One of these 'issues' may well be the way that power is used in medical settings. This seems to be the case and the investigation of power dynamics is finding its home in contemporary research regarding disabled people.

When investigating the notion of power and how it is used in rehabilitation settings, one particular study criticises the neurological rehabilitation process as resulting in the creation of governable and

ultimately controllable 'body subjects' (Sullivan 2005: 27). Martin Sullivan (2005) carried out ethnographic research within a neurological rehabilitation unit in New Zealand. For Sullivan, a focus on the power dynamics within the rehabilitation unit provided the perfect example of how 'appropriate methods of correction and rehabilitation are ascertained in order to restore deviant bodies to the norm' (Sullivan 2005: 29). Sullivan also cites the way that during their rehabilitation his respondents' bodies were divided into parts according to their 'normal' position in the functioning human body. Each of these parts received 'calculated training' (Sullivan 2005: 36) with the aim of restoring 'normal' function. Sullivan observed that none of this 'correction' and 'training' took into account the individuality and individual needs of the participants.

Following Sullivan's investigation, there is a need to appreciate that when discursive practices which emphasise the importance of normativity are considered the ideal outcome (such as rehabilitation) there must therefore be serious psychological implications for those that do not meet this standard of normativity (Vicars 2011). This is an argument that becomes all the more relevant to contemporary society when we consider that 'in the government of deviance, normality has become the decisive point of orientation' (Waldschmidt 2005: 191). Thus, the process of rehabilitation may well provide a good example of where medical power is used to render deviant bodies docile in the short-term with the aim of correcting them so that they reach society's

normative standards. The aim of rehabilitation in the unit where Sullivan carried out his research seems to be to restore incorrect and deficient persons to a productive norm. However, the long-term impact of the rehabilitation process remains unknown within Sullivan's research.

Foucault asserts that a sophisticated explanation of power can be found when researchers 'base an analysis of power on the study and tactics of domination' (Foucault 1980:98). Following Foucault, I seek to explore the institutional practice of rehabilitation after ABI through an engagement with the (re)construction of identity of the participants.

The word rehabilitation has been criticised for placing 'the responsibility for change on the individual when the problem is... a social one' (Galvin 2003: unpaginated). Furthermore, Goodley (2013a) warns of the 'hidden dangers of ideology' (Goodley 2013a:77) and ideological practices such as those employed in rehabilitation. The investigation of power in rehabilitation has been said to be important (Hammell 2006). An exploration of identity (re)construction following ABI through the lens of the survivor would then need to acknowledge the use of power in rehabilitation.

It has been asserted that rehabilitation is an example of an institutional practice which is based upon taken for granted truths and seeks to 'restore' recipients to a level of 'normal' function (Gibson et al. 2009; Gibson et al. 2012; Magasi 2008). Indeed Gibson and Teachman (2012) comment that 'the clinical focus [of rehabilitation] is most often either on repairing the biological body and/or helping the individual to adapt their environment through maximising their existing abilities' (Gibson and Teachman 2012: 476).

Furthermore rehabilitation and healthcare more generally are guided by basic societal assumptions concerning what a successful outcome may be (Gibson and Teachman 2012). Gibson and Teachman (2012) continue and assert that as a result these beliefs remain largely unproblematised and are reflected in much clinical practice. An appreciation of the societal acceptance of these unproblematised beliefs (Gibson and Teachman2012: Hammell 2006) would indicate that ABI survivors' lives are classified according to how they compare to the societal understanding of the 'normal' body. Therefore it would be sensible to suggest that these understandings inform rehabilitation practices. This leaves little room for a thorough exploration of rehabilitative practices directed toward and imagining how things could be otherwise (Gibson and Teachman 2012).

An example of this lack of imagination can be found in the way that notions of dependence, independence and interdependence are conceptualised in medical (and rehabilitative literature). Within such discourses 'the myriad relationships between persons with disabilities and the machines, tools, persons or animals that assist them are characterised either as dependencies and/or means to achieving independence' (Gibson 2006: 187). For disabled people such notions of dependence lead to unhelpful visions of disability which emphasise passivity and a need for care (Watson et al. 2004).

Another example of the way in which rehabilitation in particular can be said to be based around such taken for granted assumptions can be found in the way that rehabilitation is conceptualised as something that only occurs at fixed times and in fixed places. It has been stated that current thinking on disability is centred on 'rethinking the marginalisation of disabled people and an opening up of the field to a diversity of critical social and cultural theorizing' (Meekosha, Shuttleworth and Soldatic 2013: 320).

Meekosha, Shuttleworth and Soldatic (2013) call for research which draws attention to the link between public and private troubles and research which contextualises 'the disability experience from a position of transformative change' (Meekosha, Shuttleworth and Soldatic 2013: 321). The notion of 'transformative change' highlights

the importance of time in the (re)construction of identity. Therefore, considering this assertion it would follow that an investigation of the role of power in the (re)construction of identity of ABI survivors may need to focus upon more than the exchange of power in rehabilitation settings.

The absence of the long-term impact becomes all the more important following Erevelles' (2002, 2005) assertions that contemporary theories have been said to be promoting the view which suggest that the (human) body is a constantly developing organism which is forever being '(re) configured by multiple and competing discursive arrangements' (Erevelles 2002: 28). This dictates that for research which seeks to thoroughly investigate ABI, it may well be insufficient to view long-term social reintegration simply as an expression of power. It would follow then that future research may benefit from highlighting the unsteady and fluctuating nature of residual impairment(s) and how these impairment(s) impact upon the (re)construction of the identity of an individual. For instance, if the process of rehabilitation is viewed in terms of an expression of power, then surely the effect this has on identity (re)construction demands investigation.

Viewing disabled people's lives through a Foucauldian lens (as a demonstration of power) is simply not appropriate for some scholars. Bill Hughes (2005, 2007) is one of these scholars. Crucially, we are

reminded that 'Foucault never explicitly addressed disability or impairment' (Hughes 2005: 81). This has to call into question the relevance of extrapolating Foucault's theories onto the lives of disabled people, Hughes continues, and postulates that instead of viewing impairment and disability as purely an exchange of power:

> 'An analysis of impairment will best prosper on the terrain of lived experience and meaning as these emerge out of the fluidity of every-day intersubjectivity and intercorporeality' (Hughes 2005: 88).

In focusing on the lived experience of people who have sustained ABI, and exploring the reconstruction of identity following ABI, it is my aim to (re)present accounts of such 'every-day intersubjectivty and intercorporeality', through the gathering of empirical data.

For some, the ubiquitous nature of power means it 'circulates' (Sullivan 2005: 27) and is used in a diffuse not merely a repressive way in medical institutions such as neurological rehabilitation units (Tremain 2005). However for Leonard Davis (2010), viewing disability through a Foucauldian lens is also problematic. For Davis (2010) the creation of an inflexible binary opposition between complete power and complete subjection is 'overtly sadomasochistic' (Davis 2010: 314). Even in recognising the capacity of minority groups to rise up and resist this domination, viewing disabled people as continually powerless recipients or indeed continually acting in

resistance to these repressive acts notwithstanding situational circumstances appears to be rather simplistic.

In the case of people who have sustained ABI, the creation of this binary between substantial power and consigning the expression of power from people who have sustained ABI to merely acts of resistance may be even more problematic than first appears. This is due to the much cited ability for the body to unexpectedly change and develop in people who have sustained ABI (Fleminger and Ponsford 2005; Turner-Stokes 2007). When this is viewed in conjunction with the theoretical assertion of the fluidity of identity, viewing power dynamics as a static phenomenon may well be insufficient in an exploration of the lives of those who have sustained ABI.

With regard to the way that power is used in the identification process, Foucault asserted that people are identified according to 'grids of intelligibility'. Foucault (1970, 1972, 1983) believed that these 'grids of intelligibility' allow people in to identify others according to the role they occupy in society. This identification process is enacted according to primary or master signifiers of identity. According to this schema in the case of the participants in this study, it follows that such a master signifier would be the presence of impairment (Galvin 2003).

However, as Foucault, the feminist scholar Judith Butler (1990, 1993) and many others have argued, each person's position on the grid of intelligibility depends upon the extent of deviation from the fictitious 'normal' person. The way that any given person deviates from 'the norm' therefore becomes the master signifier of their identity.

The existence of the 'normal hegemonic being' and the way the disabled body deviates from this norm has been discussed in some detail in literature related to disability issues (Davis 1995, 2002, 2010). Davis sums up the importance of norms when he states that 'the notion of normalcy makes the idea of disability (as well as the ideas of race class and gender) possible' (Davis 1995: 158). The concept of the norm and therefore any deviation from the norm must therefore directly contribute to the (re)construction of identity amongst ABI survivors. Furthermore given the heterogeneity of ABI and impairment(s) resulting from ABI it must be realised that there is no typical identity 'trait' that defines ABI. This would suggest that a thorough engagement with the identity of ABI survivors is important.

Thus far in this chapter I have discussed the importance of individual impairment(s) in the lives of people who have sustained ABI, together with a critical analysis of the role of power in the lives of people who have sustained ABI. Crucially, this necessitates a critical interrogation of the neurological rehabilitation process. In an exploration of the

(re)construction of identity following ABI, it would follow that detail needs to be paid to the experiences of life after ABI that do not take place in the rehabilitation settings as well as those that do. Such an exploration necessitates the consideration of individual and personal responses to ABI, rather than simply an examination of clinical practice within rehabilitation settings.

It has been stated that the (re)construction of identity following ABI, requires the employment (by the person who has sustained the ABI) of many techniques associated with social (re)integration (Gelech and Dejardins 2011). Furthermore, when considering my own experiences this social (re)integration occurs on an individual, heterogeneous and often informal basis. As a result, I feel it appropriate to pay close attention towards the long-term, every-day complexity of the lives of those who have sustained ABI.

An exploration of the neurological rehabilitation process following ABI would add to the rigour of any study exploring the (re)construction of identity after ABI. Before I introduce the theoretical frameworks upon which this study is based, it seems sensible for me to discuss the questions I seek to explore within this thesis.

Research questions stemming from the existing literature

After exploring existing literature regarding the identity of disabled people, people in receipt of rehabilitation and ABI survivors there appears to be a lack of evidence which explores the long-term daily details of people who have sustained ABI. Indeed it has been asserted that there is a paucity of research in the area regarding the long-term activities of a person following ABI (Lorenz 2010; Sherry 2006). In addition it has been noted that at present there is a lack of critique regarding the neurological rehabilitation process (Gibson, and Teachman 2012; Gibson et al. 2012). In particular there is an absence of critical research from the perspective of the person in receipt of rehabilitative services (Sherry 2006). Considering these gaps in literature, this thesis seeks to explore the (re)construction of identity of ABI survivors, and in so doing critiques neurological rehabilitation from the perspective of the ABI survivor. Consequently this thesis seeks to address the following questions:

- *In what ways can an exploration of the (re)construction of identity following ABI add to the existing literature regarding disability identity?*

- *What can an exploration of the (re)construction of identity following ABI add to the existing literature regarding neurological rehabilitation following ABI?*

Within the following section, I set out how a critical social scientific approach which draws upon the 'rhizomatic' and 'nomadic' qualities of identity could be used to inform the neurological rehabilitation

process. I explore how the use of a framework built upon the insights of critical social theory aligns well with the aims of my study which seek to investigate the (re)construction of identity following ABI.

Epistemological resources: A critical social scientific framework

In this study I draw upon the critical insights of the social theorists Giles Deleuze and Felix Guattari (1987/2004) and Rosi Braidotti (1991, 2003, 2006, 2011a, 2011b, 2013) and the use of the concepts of the 'rhizome' and the 'nomad' to enable me to understand the (re)construction of identity after brain injury. In terms of my research questions, my study seeks to explore the every-day details of the lives of the participants to increase understanding of their identity (re)construction. In addition to this I explore what the experiences of ABI survivors may be able to add to existing debates regarding the efficiency of the neurological rehabilitation process following ABI. It has been stated that using social theory to explore disability issues can extend our understandings of disabled people's lives and can illuminate key theoretical assertions (Goodley et al. 2012). Meanwhile neurological rehabilitation has been said to suffer from a neglect of non-experimental and exploratory approaches to research (Plack 2005), leading to interventions that rest upon taken for granted, under-theorised practices (Gibson and Teachman 2012). Therefore I seek to put these critical social theories to work in exploring what they may have to offer in understanding identity (re)construction after ABI, both in exploring the lives of the participants and

investigating their experiences of the neurological rehabilitation process. I now turn to a brief investigation of these theoretical concepts, and highlight what their use can contribute to the investigation of the lives of people who have sustained ABI. In the following section, I explore some situations where the critical, social concepts of Deleuze and Guattari (Deleuzogauttarian concepts) and in particular their presentation of the rhizome, can be used to explore the identity (re)construction of ABI survivors.

Epistemological resources: Deleuzoguattarian concepts

I will use the concept of the 'rhizome' which was used by Deleuze and Guattari in their representations of identity. The rhizome is a naturally occurring, live, organic organism (Simmons et al. 2008). It is a structure which is found in plant life. Deleuze and Guattari describe it as a structure which has 'neither beginning nor end, but always a middle *(milieu)* from which it grows and which it overspills.' (Deleuze and Guattari 1987/2004: 23) (Emphasis in original).

I introduce this concept as being relevant to the lives of my participants as it represents the removal of fixed points of reference. It adds to my (re)presentation of the lives of people who have sustained ABI by enabling me to remain open to engage with the heterogeneity and constant development of people (Goodley 2007a; 2007b) as well as critically examining whether neurological rehabilitation is a long-

term concept, which may not necessarily occur only in fixed places and at fixed times.

The thoughts of Deleuze and Guattari and their focus on continuity and development have been transposed to the subject of disability, and the lives of disabled people before. For example, Margrit Shildrick (2009) uses 'Deleuzoguattarian' thoughts to demonstrate how the very existence of disabled people questions the idea of the self- autonomous 'normal' person through their non-normative embodiment.

The Deleuzoguattarian concept of the rhizome was central to a study exploring opportunities for inclusion amongst children with the label of profound and multiple learning difficulties (PMLD) (Simmons et al. 2008). The application of fluid rather than fixed, singular identities was said to have huge implications for how society interprets the life of a person with such a label since these labels were not understood as permanent and inescapable but instead as malleable and situation specific:

> 'If disability is conceptualized in this [fluid, rhizomatic] way, then implications for inclusion emerge, especially if we challenge the arborescent, binary models that dominate special educational thinking (inclusion/exclusion, able/disable, etc'. (Simmons et al. 2008: 739)

Following this assertion, the way that binary labels such as abled/disabled are used in the lives of people who have sustained ABI is worthy of exploration.

The ability of the parents of disabled children to 'defy categorization' (Goodley 2007a: 146) was the focus of another Deleuzoguattarian themed paper which utilised the concept of the rhizome. This study of the lives of the parents of disabled children resulted in a questioning of the static fixing of (disabled) people and their allies (Goodley 2007a: 157). Rather importantly, the 'rhizome' was used to invite us to consider the constant development of identity (Goodley 2007a). Any entity in its fluid or rhizomatic form does not have a definite end point.

The concept of the rhizome is relevant to the study of the (re)construction of identity of ABI survivors as it implies the removal of pre-determined, fixed points of reference. Such a removal of fixed points of reference within the recognition of the ever-mobile aspects of identity enables a conceptualisation of the participants' lives which fluctuate according to time, place and situation. The concept of the rhizome can direct us towards viewing life as if it was not a linear, predetermined entity with a definite 'end in sight', but instead as a journey with checkpoints along the way.

In the following section I describe how the analysis of the 'nomad' has also been utilised in explorations of disabled people's lives. This is a concept that was introduced by Deleuze and Guattari (1987/ 2004) but has been further explored, extended and integrated into the contemporary social arena by the feminist theorist Rosi Braidotti (1991, 2003, 2006, 2011a, 2011b, 2013).

Epistemological resources: Braidottian concepts

In using the term 'nomadism', I use this term not in its geographic sense, but in a figurative way, to refer to change and reformation (Braidotti 2011a; Roets 2009; Wyatt et al. 2011). This is a notion that I introduced above as possibly being most relevant when (re)presenting the lives of people who have sustained ABI. Rosi Braidotti (2011a) provides an example of the capacity of the concept of the nomad to represent the fluidity and unpredictability of life, by stating how this concept helps her with the description of her personal biography:

> 'The figurative approach to nomadism will allow me to play on the associative quality of the nomadic state and therefore tap on its metaphorical richness. I will proceed by exploring some of the cognitive and affective resonances of the image of the nomad, riding on its back, so to speak, toward a horizon that I cannot always predict.' (Braidotti 2011a: 29)

Braidotti sums up the transformative power of the image of the nomad. The uncertain and unpredictable nature of the future is also encapsulated. The image of the nomad seems to align with the unpredictability of the future. Furthermore, the image of the nomad seems to guide us towards viewing life as a constant transition or becoming rather than a linear process.

A recent paper which explores the life worlds of members of the self-advocacy movement within those people that are labelled as having learning difficulties demonstrates how the philosophical concept of the nomad can be used to explore the lives of disabled people. Within this paper (Roets 2009) the life of a person who is described as having learning difficulties is explored. It is argued that people who are responsible for 'caring' for the 'patient' (the person described as having learning difficulties) become uncomfortable at the mere sign of the 'person requiring care', or 'the patient' exercising autonomy in another part of life. The concept of the nomad was used to (metaphorically) demonstrate the way that people with learning difficulties are commonly conceptualised as always being passive recipients of care. The way that the participant was able to act with autonomy and independence and thus demonstrated the 'nomadic' qualities of identity disturbed other 'normal' members of society. In demonstrating autonomy and independence, people with learning difficulties 'critically challenge the power of the dominant master narrative about them' (Roets 2009: 697).

In a similar paper (Roets and Goodley 2008) the concept of 'the nomad' was once again used when exploring the lives of people with learning difficulties. It was observed that the identity of people with learning difficulties could be described as 'nomadic'. This was due to the demonstration of the ability of the person with learning difficulties' identity to constantly be on the move inhabiting a whole range of subject positions to 'avoid [the] voyeuristic eye of intrusive professionals' (Roets and Goodley 2008: unpaginated).

The lives of people who have sustained ABI are often subjected to scrutiny, both within rehabilitation units themselves (Gill 2012) and also as people strive to (re)construct their identity and live their lives in society (Mills 2011; Sherry 2006). This study seeks to highlight the way that the gathering of everyday, seemingly mundane experiences can add to an exploration of identity. When the everyday experiences of ABI survivors are engaged with, the dominant discourses that underpin institutions such as rehabilitation units are cast aside, leaving space for critical interrogation. This study recognises both the interconnection of lives, and the unstable, unpredictable and 'nomadic' nature of the lives of the participants. Therefore, the use of Braidotti's contemporary theoretical observations are undeniably relevant in this study of the (re)construction of identity following ABI. Furthermore, the concept of the nomad is also of great relevance to my study as it enables an affirmative conceptualisation of identity which entails the 'rejection of false universalism (and) the affirmation

of the positivity of difference' (Braidotti 2013: 11). In her latest text, Braidotti draws on her use of the nomad to suggest that perhaps we may now be entering the age of the posthuman. Braidotti suggests that:

> 'The posthuman condition urges us to think critically and creatively about who and what we are actually in the process of becoming' Braidotti 2013: 12).

Braidotti's concept of the 'nomad' is an appropriate concept to use in my study as I wish to investigate whether people who have sustained an ABI can, if they indeed wish to, also critically challenge the view, or 'dominant master narrative' (Lyotard 1979/ 2004) which positions them in a fixed, passive, subordinate location. The use of Braidotti's concept of the nomad enables me to remain open to the way my participants view their identity (re)construction after their ABI.

In the coming section, I will outline in a little more detail some of the ways that the philosophical thoughts of Braidotti and Deleuze and Guattari can be utilised to explore the identity (re)construction of the participants. I am particularly interested in exploring the way that the 'rhizomatic' (Deleuze and Guattari) and 'nomadic' (Braidotti) nature of identity may have the ability to transfer the focus from what our bodies represent at a given time to what they may represent in the future (Goodley 2007a). Simply put, this guides us to consider life as a process of *becoming* rather than *being* (what we are at a given time).

The investigation of the future and what we are becoming would seemingly be particularly important when considering the lives of people who have sustained ABI, as the extent to which their impairment(s) will affect their lives is largely unknown.

Utilising epistemological resources: Towards a fluid rehabilitation?

I have briefly outlined some situations where the philosophical thoughts of Braidotti and Deleuze and Guattari have been considered to be most appropriate to analyse and interpret key aspects of disability. I now continue with a consideration of the possibilities that may exist for the use of critical, social theories such as those presented above, when researching the lives of people who have sustained ABI. The use of such theories can result in research that remains open to emphasising the fluid capacity of (disabled) identity and in so doing enables the creation of space for the inclusion of the long-term daily details of this to the lives of people who have sustained ABI. Following Braidotti (2011a) the use of these frameworks does not aim to conceptualise ABI as a purely social or indeed a purely medical entity, rather it allows for the accounts of people who have sustained ABI be understood. I suggest that these accounts contain vital insights into the complexity living life following ABI.

The identity of a person has been said to have 'rhizomatic' (Deleuze and Guattari 1987: 2004) and 'nomadic' (Braidotti 1991, 2003, 2006, 2011a, 2011b, 2013) qualities. I intend to utilise these concepts to investigate the long-term social integration of people who have sustained ABI. The purpose of the use of these concepts is to represent the possibility of people who have sustained ABI retaining a certain degree of control over their lives. The use of such concepts would investigate the ability of people who have sustained ABI to change subject positions and (metaphorically speaking) dance around the pathologising judgements of others. It would follow that the use of these concepts could subvert any (externally imposed) conceptualisation of brain injury survivors' lives which seeks to permanently fix them to acts of passivity. Furthermore, the use of the concepts of the rhizome (Deleuze and Guattari 1987/2004) and the nomad, first introduced by Deleuze and Guattari (1987/2004) and further developed by Braidotti (1991, 2003, 2006, 2011a, 2011b, 2013) will allow me to remain open to engage with the accounts of my participants rather than attributing those accounts to pre-existing (rights-based) discussions of disabled people's lives (Mercieca 2011).

Elsewhere, within research that seeks to explore the lives of disabled people, it has been observed that the static labelling and fixing of the identity of disabled people is problematic (Goodley 2011; Goodley and Roets 2008; Roets and Goodley 2008) and identifying a person as disabled notwithstanding the circumstance, seems to devalue their

existence. This is a particular problem when viewing people in terms of binary opposition; as care receivers as opposed to care givers. This notion is pertinent when exploring the lives of people who have sustained ABI, as in certain situations some individuals may require care. However, in other situations or aspects of their lives they may not require such care. One can discover that within the growing body of literature that seeks to (re)present the complexity of disabled people's lives, there is a burgeoning trend to analyse empirical data using 'Deleuzoguattarian' (eg. Goodley 2007a; Goodley 2007b; Simmons et al. 2008; Slater 2012) and 'Braidiottian' (Goodley and Roets 2008; Roets 2009; Roets and Goodley 2008) frameworks.

If we view life as an fluid entity, where we are constantly growing, this could have important implications for the way society considers any 'category' of people (such as those who have sustained ABI) who deviate from the dominant so-called 'normal' way of being in the world. This view of life enables a greater acceptance of difference and diversity. With regard to my research, such a viewpoint could well be used to critique taken for granted assumptions in neurological rehabilitation, as it can offer the opportunity for those who have residual impairment(s), to escape wholesale judgements, which are based solely on a single aspect of their identity. A study that uses the critical concepts of the 'rhizome' and the 'nomad' to analyse the reconstruction of identity of ABI survivors would add to existing

literature regarding ABI/disability identity as well as neurological rehabilitation following ABI.

In drawing upon the experiences of people who have sustained ABI in early adulthood, I seek to explore and better understand the forces that (re)construct identity. I suggest that the identities of the participants can be better understood through the use of a 'rhizomatic' and 'nomadic' framework. As a 'single incident' injury, ABI provides an ideal terrain to discuss the complexity of identity formation, not least as it necessitates a wholesale change in a person's sense of self (Gelech and Dejardins 2011; Lorenz 2010; Sherry 2006). Experiencing brain injury constitutes a change or a 'rupture' (Zittoun 2004: 131) in a person's life. It has been stated that:

> 'Transitions that follow such ruptures, offer a window on processes of change at the level of skill acquisition, identities and also meaning construction' (Zittoun 2004: 131).

Regarding change or 'rupture' in this way allows an affirmative conceptualisation of the identity of brain injury survivors as it remains open to the possibility of 'skill acquisition' within an exploration of identity (re)construction. Moreover, researching the lives of people who have sustained ABI is of particular interest, not least in so far as medical intervention is an obvious requirement in the immediate post-injury stage. However, as time elapses, the focus of

attention may shift from the biological, medical and absolute, to the shaky, subjective and unpredictability of the future. In short, the biological must meet the sociological; the objective must meet the subjective. Thus, any attempt to explore long-term identity (re)construction after ABI would need to become familiar with the subjective life experiences of survivors.

In seeking to depart from traditional medical discourses, some have criticised previous research concerning disabled people as being overly reluctant to acknowledge the influence of such notions as embodiment in the lives of disabled people (Shakespeare 2006). Within this thesis the empirical data I present seeks to engage with both the medical and the long-term social factors which simultaneously act upon the lives of my participants.

At the same time however, in using an analytical framework based on critical social scientific theories, I also hope to avoid relying on the dominant, common sense understandings of neurological conditions such as ABI (Gibson and Teachman 2012). The use of my analytical framework allows me to remain open to engaging with the complexity of the identity of the participants.

When viewing the (re)construction of the identity of the participants through a critical lens, it has been stated that this may encourage a resistance to dominant, common sense understandings of neurological conditions such as ABI (Gibson and Teachman 2012). This permits researchers to reflect on the 'larger socio-political systems' (Gibson and Teachman 2012: 474) that are in play during interventions such as rehabilitation. Thus, a sophisticated understanding of both the lives of ABI survivors, and the workings of ABI rehabilitation are necessary for a critical understanding of the (re)construction of identity following ABI. The extent to which various impairments are conceptualised as 'real' (Barnes 2012; Goodley 2013a; Shakespeare 2011) would therefore be of great concern to any study that seeks to utilise explanatory power of critical theories. I would have significant difficulties if I attempted to explain to my participants that I did not consider their brain damage to be 'real', but rather it was purely a social construction, borne out of the power of discourse. However, to reduce this debate to a single issue seems to be an oversimplification. Thus, in this thesis, I prefer to reflect on the lives of my participants and seek to determine the extent to how their experiences may highlight (or not) the 'reality' of their brain injury.

Importantly, it has been stated that ABI does not refer to a single impairment and no two brain injuries are ever the same (Saateman et al. 2008). This assertion may then be used to problematise any viewpoint which conceptualises ABI as a singular 'thing'.

Furthermore, I would argue that to speak of brain injury as a 'brute fact' only seems to deny the oppression that is entangled with the label of brain injury. Ultimately however, an exploration of the every-day activities of the participants and how these activities fit into the overall identity (re)construction will permit a greater understanding of the way that participants conceptualise their ABI.

I draw on the insights of critical theories and how these insights have influenced how bodies and minds are conceptualised. I recognise the way critical theory guides us in a consideration of the 'reality' of the body. The integration of multiple influences on how bodies and minds are constructed is summed up by Braidoti:

> 'The body or the embodiment of the subject is to be understood as neither a biological nor sociological category but rather as a point of overlapping between the physical, the symbolic, and the sociological' (Braidotti 2011a: 25).

This conceptualisation calls for an investigation of the body that comprises of more than simply an interrogation of the corporeal, fleshy aspects of people's lives, but rather an investigation that encapsulates the diversity of lives, and draws upon 'the physical, the symbolic the sociological' and how they may interact in unique, unexpected ways. This call seems to align well with a 'rhizomatic' and 'nomadic' exploration of the (re)construction of identity of the participants in this study.

As well as considering insights that critical theories offer to discussions of the 'reality' of ABI, it seems worthwhile reviewing this literature that is concerned with discussing the 'reality' of other impairments/labels. When researching the lives of people who have 'learning difficulties' Goodley (2011) seems to point towards the social construction of people with the label of Down Syndrome. In highlighting the factors which suggest the social construction of Down Syndrome, Goodley provides a relativist account of disability. He states that when realists refer to the 'reality' of a phenomenon (in this case Down Syndrome) they '...ignore the social construction of the facts they describe. To suggest Trisomy 21 is a brute, biological fact kicks away its deep historical construction.' (Goodley 2011: 117). He suggests that close attention needs to be paid to the politics associated with such a label. In other words, one cannot divorce impairment from the socio political implications of being so labelled.

Meanwhile, when referring to the most effective way to explore impairment through an engagement with the daily details of people's lives, others including Nick Watson (2012) suggest that a critical realist stance is preferential. Critical realism is described as a way of viewing disability which combines the 'social processes of structure and agency that shape and reshape one another over time' (Williams 1999: 809). This approach is said to permit an engagement with the daily details of people's lives, without excluding or banishing medical tenets to the domain of medicine. This way of theorising disability is

said to avoid 'downplaying the role of the impairment in the lives of disabled people' (Shakespeare 2006: 50). Furthermore Watson (2012) states that:

> 'A critical realist agenda enables us to move beyond debates about what is disability and how it should be defined and what is or is not an impairment and what is the relationship between impairment and chronic illness and disablement. It also permits an examination of the experiential basis of impairment and an exploration of the day-to-day problems associated with living with a condition without reducing the disease to a social construction or creation' (Watson 2012: 102).

For Rosemary Garland-Thompson (2011), the critical concept of the 'misfit' is important to disability theorisation. Her 'material-discursive' approach seeks to interrogate the intersection between the material 'reality' of impairment and the externally imposed discourses and environments that shape our lives.

Garland-Thompson states:

> 'Our conventional response to disability is to change the person through medical technology, rather than changing the environment to accommodate the widest possible range of human form and function. The concept of misfitting shifts this model. The body is dynamic, constantly interacting with history and environment; sometimes it fits and at other points or moments, it does not. We evolve into what we call disability as our lives develop. The misfits that constitute the lived experience of disability in its broadest sense is perhaps, then, the essential characteristic of being human (Garland-Thompson 2011: 603)

Garland-Thompson suggests that viewing disability as a 'misfit' may help to transfer the focus away from bodily deficiencies, towards a more sophisticated understanding of limitations of our environments. Furthermore, Garland-Thompson argues that politics should be directed by our wants and desires, not by a static notion of what we are at any given time. Crucially, the increased focus on the future; on *what we may become*, may well call into question the importance of a static description of our current materiality; *what we are.* Therefore, if static notions of what constitutes ABI are rejected, then this may question the ability of research to demonstrate the 'reality' of such a phenomenon.

In my study of (re)construction of identity after ABI, I intend to utilise the explanatory qualities of critical social theory to explore the identity (re)construction of the participants without relying on pre-existing perceptions of ABI or disability in general. Rather, in my study I use an analytical framework which enables me to remain open to engage with the experiences of the participants without closing down opportunities for future growth and development.

Rather than unproblematically accepting taken for granted assumptions (such as those concerning the 'reality' of ABI), this study seeks to learn from the experiences of the participants, and what they consider to be important in their identity (re)construction. This

study will contribute towards the body of evidence which investigates what is made possible by learning from the experiences of ABI survivors, together with demonstrating the ways in which the integration of their experiences into the social arena add to debates about key concepts concerning disability, identity and rehabilitation after ABI.

Negotiating a space within existing literature concerning the (re)construction of identity following ABI

In my study, I will engage with the participant experiences to achieve a greater understanding of their (re)construction of identity after their ABI. Although this thesis does not seek to and cannot possibly provide complete a neat, precise explanation of the way identity is (re)constructed after ABI, an exploration of the identity of my participants will certainly contribute towards demystifying the lives of ABI survivors.

Furthermore, I employ a critical framework which remains open to viewing life as a fluid, unpredictable journey. As a result, research within this framework may well be able to disrupt the view that rehabilitation following ABI is simply a short-term notion. My research remains open to emphasising the fluidity and changeable nature of people's lives after ABI. If neurological rehabilitation after

ABI is conceptualised as a long-term notion, then this assertion may have important consequences on the claims that are made about people's life after ABI.

My research seeks to engage with the long-term, everyday activities of people who have sustained ABI. Within this research, I seek to come to terms with, and explore the boundaries of the neurological rehabilitation process after ABI. Thus, in exploring the (re)construction of the identity of the participants, it is possible to explore the participants' opinions regarding the discursive practices which helped or hindered their rehabilitation.

In western, neoliberal society rehabilitation units are often taken for granted physical spaces where this rehabilitation is thought to take place. The inner workings of such units are often considered sacrosanct and eliminated from critical interrogation (Gibson 2006; Sullivan 2005) hence there has been little problematisation of the foundational premises of rehabilitation (Gibson and Teachman 2012; Gibson et al. 2012). A thorough investigation of the discursive underpinnings of rehabilitation including the interrogation of ideas around the length of rehabilitation and what is meant by the notion of rehabilitation, could nevertheless offer a more sophisticated understanding of rehabilitation. A critical appraisal of the every-day

practices within institutions such as rehabilitation units is necessary to examine the ideological notions that support these (neoliberal) institutions (Goodley 2013a). I seek to build upon recent developments in disability studies which encourage a critical examination of taken for granted assumed 'truths' which sustain such processes as rehabilitation (Goodley 2013a; Shildrick 2012).

In utilising the thoughts and opinions of those who have sustained ABI I am contributing to traditional debates regarding ABI from within the medical sciences. I draw on influences from social scientific theory to explore the activities that comprise the (re)construction of the identity of the participants which will highlight the ways in which in which rehabilitation contributes to such identity (re)construction.

In its use of critical, social scientific theories, this study therefore seeks to critique rehabilitation from an interdisciplinary perspective. I use theoretical insights alongside the experiences of my participants to suggest a more long-term, future orientated vision of rehabilitation. This may allow a view of the rehabilitating body as a site of nomadic possibility; of unpredictable potential, rather than an assemblage of parts with a clear destination driven by society's norms and expectations. The clinically based literature emphasises that

neurological rehabilitation strives to increase the skills and proficiencies of people who have sustained ABI, but what appears to be less clear is how the acquisition of these skills and proficiencies are implemented by the person who has sustained ABI to aid their individual life journey.

Conclusion

I have argued that the literature pertaining to the (re)construction of identity following ABI and literature regarding the neurological rehabilitation process after ABI that exists has not sufficiently theorised how people who have sustained ABI wish to and indeed do live their lives on a long-term basis. Research concerning acquired brain injury has almost always been confined to the medical arena. This may well be the reason for the long-term effects of ABI being largely ignored.

In using a critical, social scientific framework in my research, I feel able to contribute to the body of literature concerning ABI and my study is aimed at contributing towards addressing this gap in knowledge. This is achieved by paying close attention to the seemingly mundane day-to-day activities in the lives of my participants. In light of this absence of knowledge pertaining to long-term neurological rehabilitation, my study seeks in some small way

and on a very small scale to achieve the gathering of empirical evidence to disrupt the tradition of ignoring the long-term effects of ABI. My study explores some of the ways that people who have sustained ABI live their lives. This exploration of the (re)construction of identity of ABI survivors is conducted through a critical, social scientific lens.

Chapter 3 Mapping the terrain: theorising my identity (re)construction after ABI

Introduction

In this chapter I present my personal experiences of identity (re)construction. These aspects of my personal biography contribute in my critical exploration of how the insights that ABI survivors can offer to the theorisation of 'disability identity'. In addition, I use my analytical framework to explore the neurological rehabilitation process after ABI through the lens of the ABI survivor. Crucially it has been stated that there is a paucity of research which explores issues pertaining to ABI from the perspective of the survivor (Sherry 2006). Being an ABI survivor, I believe that I have an intimate connection with the experiences of my participants both in terms of a theorisation of 'disability identity' and also neurological rehabilitation after ABI. Considering this, it would be sensible to suggest that sharing my personal experiences of rehabilitation serves me well in contextualising the project.

In being an ABI survivor, I have to consider the potentially problematic belief that I know all about brain injury and its effects. Thus, given the heterogeneity of brain injury and the exploratory nature of this project I have consistently sought to frame my personal

experience of identity (re)construction after ABI within an engagement with the experiences of my participants. As such, any assertions that I make within this chapter are based solely on the analysis of my own experiences and are not an attempt to represent those of participants or indeed those of all ABI survivors. That said, I do not wish to totally downplay the importance of my experiences. I share my experiences of identity (re)construction before I introduce the participants as acknowledgement of the way my identity has influenced and guided this study. It has been stated that it is necessary to acknowledge the impact that researcher identity has on any research project (Tregaskis 2004; Harvey 2013; Letherby et al. 2012). Following these assertions, I regard it appropriate to include a chapter which seeks to explore my own experiences and therefore contextualise the project. Thus, it is within this chapter that I attempt to 'theorise my subjectivity' (Letherby et al. 2012). I turn towards that of the participants in a later chapter. 'Theorised subjectivity' is defined as '... a reflexive approach that acknowledges the significance of both intellectual and personal auto/biography of researchers and of respondents' (Letherby et al. 2012: 90) which leads to reliable and ethical knowledge production which will also be of some use in the social world. In other words, within this chapter I discuss some of my experiences that have helped to shape my opinions on the identity of ABI survivors; research involving ABI survivors; and some of the ways that research can aid the continual improvement in rehabilitation service provision for ABI survivors.

By presenting my own experiences of identity (re)construction after ABI, I also seek to demonstrate how my experiences, my influences are unique. Many of the substantive issues that I explore resonate with the experiences of the participants and are therefore further interrogated in the remainder of the thesis. This chapter 'maps out the terrain' of the thesis somewhat, providing the reader with a corporeal and embodied introduction to the core issues on which this thesis is based.

Subjectivity in identity (re)construction after ABI

My epistemological opinions regarding ABI are firmly rooted within the consideration that subjectivity is important. Put simply, I believe there is no one overriding 'truth' regarding the subject. Rather there are several 'truths', which vary hugely in value depending on the position that is occupied within the rehabilitation process. For example, within an acute healthcare setting, the role of a neurosurgeon would be to protect the life of the ABI survivor against the immediate threat to life that is posed by ABI. However, later on in the rehabilitation journey, a neurological psychotherapist may be charged with the task of aiding a person to be able to understand and interpret new information. At the same time, a physiotherapist may be required to help the person transfer safely from seating position to a standing position. There are, of course, many other rehabilitation professionals involved in the rehabilitation process. The example above is provided in order to emphasise the point that different people

will have vastly different aims and goals within the rehabilitation process. Lastly, there is the heterogeneity of brain injury or put simply the way that each brain injured person is a unique individual with a unique set of needs.

Therefore, there are inevitably going to be many varying opinions regarding ABI; identity (re)construction following ABI; and the neurological rehabilitation process. These opinions vary in large part due to the vastly different perspective that different people have according to their subjective relationship to ABI; the (re)construction of identity following ABI; and neurological rehabilitation. This thesis seeks to re-present the perspectives ABI survivors, which is a perspective which has been said to historically ignored (Sherry 2006). Following Sherry (2006), this thesis seeks to engage with rather than ignore this perspective.

Epistemological journeys

During my adult life I have wholly changed my epistemological beliefs; my views about how knowledge is produced and the most effective way to produce knowledge. Over 10 years ago when I was deciding upon a suitable topic for my physiotherapy dissertation (which I never began), I remember talking to my peers and expressing my scepticism at the value of knowledge that was not objectively obtained and statistically 'proven' to be 'true'. During my inpatient

rehabilitation, I began to question this belief regarding the intricacies of the value of knowledge in healthcare environments. I was now turning toward an acknowledgment of the value of the experiences of people who have sustained impairment(s). This in turn led me to consider the many possibilities that narrative approaches to research and re-presentation may offer. In short, my beliefs on the knowledge production process had changed from a wholly quantitative stance which promoted 'truth' seeking approaches and the process of accruing 'facts', to one that is far more subjective in nature where I believe brute 'facts' to be an unrealistic fallacy.

I do of course acknowledge the way that the training I have received in social science research may well have influenced my initial standpoint. Moreover, I also believe that my own view has been influenced by those around me; by friends; colleagues; supervisors and so on. An approach that accepts the way that neurological rehabilitation after ABI is charged with integrating biological sciences with that of the more imprecise complexities inherent with long-term social integration seems relevant. Despite this, neurological rehabilitation has been criticised for a lack of criticality of its foundational premises (Gibson and Teachman 2012) and its reluctance to engage with the experiences of ABI survivors (Sherry 2006).

The way that my epistemological beliefs have shifted with the passing of time serves me well in demonstrating the way that our opinions; our lives are to a large extent shaped by the influences around us and these opinions are far from fixed and static entities, but rather are 'rhizomatic' and 'nomadic' in nature and retain the ability to mould, change and transform over time due to the complexity of our experiences. Moreover, the shifting nature of my epistemological beliefs and the recognition of their malleable nature aligns well with an analytical framework which stresses the 'rhizomatic' and 'nomadic' fluidity of identity and its contribution to identity (re)construction following ABI. I now seek to explore how these epistemological debates may help to inform rehabilitation research and practice.

In neurological rehabilitation there is a need for outcomes or 'goals' of rehabilitation to be set with the individual and set according to that person's short-term as well as long-term goals (for example, Barnes 2003; RCP and BSRM 2008; Department of Health 2005; Playford et al. 2009; Turner-Stokes 2008; Turner-Stokes et al. 2005; Wade 2009) (goal directed rehabilitation is discussed in greater detail in the introductory chapter). An acceptance of this provides a firm justification for the gathering of ABI survivor experiences. This is undoubtedly a positive aspect of the rehabilitation process. Furthermore and in accordance with statutory guidelines, the adaption

and updating of these goals is continual within formal rehabilitation settings (RCP and BSRM 2003; Department of Health 2005).

However, as a person who has sustained ABI, and is still navigating the rehabilitation process, I have doubts that this is an achievable target. When concerning long-term goals in particular, the way that rehabilitation is charged with predicting future life events would seem to be a problematic notion. According to many contemporary theoretical assertions such as those provided by Deleuze and Guattari and Braidotti, life is 'rhizomatic' and 'nomadic'. Given this view, it would follow that in the case of a person who is rehabilitating after ABI the future activities could not be predicted. Furthermore, certain tasks or activities may be considered as 'rehabilitative' and certain activities may not be considered 'rehabilitative'. I am unsure as to how rehabilitation (in its current form) can account for the role of and classify, activities in long-term rehabilitation. I am also uncertain as to how rehabilitation in any form can hope to envisage the uncertain activities of contemporary life. The acknowledgement of the 'rhizomatic' and 'nomadic' nature of identity can help me understand the uncertainty and changeable nature of the activities involved in long-term rehabilitation of the participants, and their (re)construction of identity following ABI.

Despite efforts to make rehabilitation 'patient centred' (Turner-Stokes et al. 2005) and meaningful to the individual, this may be problematic in the (re)construction of identity after ABI. If life is considered in a way which acknowledges its inherent unpredictability (Braidotti 2011a, 2011b; Deluze and Guattari 1987/2004), any framework which purports to 'rehabilitate' based upon a fixed- or at best a time-limited conception of embodiment may well be problematic. To provide a brief example, I have been long since discharged from rehabilitation services, but yet firmly believe that I am still rehabilitating and (re)constructing my identity. Further I am not sure I will ever consider myself to be 'fully' rehabilitated. This is because the word 'rehabilitation' means different things to different people, based upon individual, subjective and time-dependent factors. In my own life I prefer to situate my period of neurological rehabilitation into my overall life journey. As my life changes, so does my identity, my identity never stays still, meaning that my period of neurological rehabilitation simply represents a period of time in my life. Contemporary social theorists remind that life is a journey whereby priorities, targets and aspirations are constantly shifting amid an environment of near continual re-appraisal and re-prioritisation.

In acknowledgment of the constructed and flexible nature of knowledge, I consider it sensible to set out some of my life experiences which have helped to guide my beliefs. I therefore turn toward sharing some aspects of my personal biography that are

related to my period of neurological rehabilitation. These experiences are shared with the aim of portraying the corporeal aspects of brain injury. In sharing these embodied experiences, I seek to contextualise this research by enabling the reader to make sense of some of my life experiences and those in my identity (re)construction which have led me to this research project.

My rehabilitation experiences

Throughout my childhood I had always been interested in healthcare, and therefore decided that I would like to have a career which was in some way connected with healthcare and healthcare provision. Thus when I was 19 years old, I went to university to study a three year physiotherapy degree course. I managed to negotiate the demands of the course without too many problems, in the first year and half of the second year, until I sustained a severe traumatic brain injury that would alter the direction of my life. It was when I was at home catching up with a few old school friends in the Easter break that I fell from a recreational area, roughly 25 feet onto a concrete car park.

From a purely medical perspective the nature of my injury was thus. I sustained a severe traumatic brain injury, with damage primarily located in the brain stem area of my brain. As far as I am aware, the majority of the damage occurred in the day or so following the accident, as my brain began to swell within my skull. I have

purposely included only the basic details here as since speaking to my neurological consultant, I have been informed that the precise nature and extent of my brain injury was unclear even to many medical professionals.

My early encounters in hospital mainly consisted of medical and nursing care designed to help me achieve medical stability. These encounters were punctuated by physiotherapy, speech and language therapy and occupational therapy sessions, but at this stage reaching a position of medical stability was of course the greatest concern. I was in the acute hospital for four weeks after the initial accident, when I was transferred to a specialist neurological rehabilitation unit. I remained an in-patient within the neurological rehabilitation unit for roughly seven months.

Upon reflection I believe I received a good standard of care during my time at the neurological rehabilitation unit, despite the odd murmuring of discontent regarding my cognitive abilities that were based upon the results of clinical tests. This annoyed me greatly and from this grew my intense dislike of 'clinical tests' and the hugely problematic long-term prophecies that are made upon the results of these. The future destiny of ABI survivors is something that is markedly absent from current literature regarding ABI. Nevertheless, for me, my discharge from in-patient care signalled the beginning of

the main part of the rehabilitation process; I was about to begin to attempt to re-formulate the key aspects of my life and in so doing (re)construct my identity.

After my discharge from the inpatient neurological rehabilitation unit, I began and completed a computer course that increased my basic computer literacy skills. Upon completing this, I learned to drive. When I had completed my driving test, I considered the time to be right to return to the workplace. I worked in the accounts department of a local business for roughly one year. Upon reflection, these activities which I took part in for roughly three years after my discharge from the rehabilitation unit were initially conceived by myself as 'a good way to spend time', were some of the most important activities in my on-going rehabilitation and identity (re)construction. I believe this because it was during this time that I was able to slowly integrate back into society. I was able to take time to recover my interest in socialising and discover what I wanted to achieve with the rest of my life.

During the period of time immediately following my discharge from inpatient neurological rehabilitation services (November 2003) and the end of the second year of my undergraduate degree (April 2009), I received treatment from a private physiotherapist who was a consultant in rehabilitation. These sessions lasted one hour per week.

Within the treatment sessions, we concentrated on activities that were designed to improve my balance and my gait pattern. These sessions were hugely beneficial, and to a large extent were successful. However, although initially my main goal was to walk independently, when I decided to no longer continue with these sessions I was still mobilising with the aid of one crutch. I decided that I no longer deemed it worthwhile to dedicate this amount of time to physiotherapy.

Towards the end of my outpatient physiotherapy treatment in early 2007, I realised that I wanted to return to study in higher education. Due to my ABI, and the resultant impairments that came from this, I was no longer able to embark upon any course which required much physical strength. However, my interest in healthcare and society in general had not waned. I considered a general health and social care course to be suitable for me. Thus, in 2007 I began a three-year degree in health and social care studies at a local university.

I felt I had reached a stage in my rehabilitation whereby I thought it was unlikely that I would be able to walk independently in the near future. Moreover, I decided that I had reached the time where I had to scale back the amount of time I dedicated towards 'official' rehabilitation. By completing seemingly mundane tasks such as visiting the university; walking to the shops to get some milk and so

on, I would still be contributing to my rehabilitation. Therefore, the juncture between rehabilitation and the resumption of 'normal' activities was and continues to be a crucial and overlapping part of my identity (re)construction after ABI and my life. My undergraduate course provided a good opportunity to learn and immerse myself in an academic environment once again, without being too intellectually taxing. For me, my return to education was a hugely significant part of my identity reconstruction after ABI.

It was during the final year of this course that I was introduced into some specific areas of health and social care in far more detailed way. I found myself drawn to a module termed 'Working with Disabled People'. I felt that I as a disabled person had an important voice within this academic arena; and one I was determined to utilise. During a university seminar, I met a professor from another university, who was very supportive of my idea for continued involvement in academic pursuits. With a great deal of help provided through contacts within the university, I managed to secure a scholarship to enable me to study for an MSc in Social Research to begin October 2010.

During my time as a taught postgraduate student, my interest in healthcare became focused more specifically on research in health and social care. At this time I was convinced that I would like to

embark upon a career in teaching and research within health and social care, and thus began the search for funding to enable me to tackle a PhD. I managed to secure a studentship to study a three-year PhD course.

Even at this time, although I knew I wanted to involve people who had sustained ABI in my research, I was not sure of the exact focus of my study. Following the initial year of the PhD, I successfully negotiated the probationary period which culminated in me giving a presentation and discussing my proposed research in some detail with established academics. Then next task was for me was to achieve ethical clearance for my proposed research from both the university and the organisation in which I planned to complete the interviews. I planned to carry out some in-depth interviews with young people of a similar age who had sustained ABI. These interviews were to be carried out within a voluntary organisation that I had been working within for roughly six months. After a little probing from the ethics committees, data collection was cleared by both the university and the voluntary organisation. I was now ready to start data collection.

The experiences I have shared of my own identity (re)construction align with a 'rhizomatic' and 'nomadic' vision of rehabilitation as my experiences highlight the unbounded nature of my rehabilitation, and the way that it is not limited by time and place. My rehabilitation and

identity (re)construction take place in a host of diverse spaces and at unexpected times, thus highlighting the potential for a consideration of the 'rhizomatic' and 'nomadic' nature of identity (re)construction and rehabilitation.

There are many parts of my life which remain excluded from this description. Within the sections that follow I attempt to outline just some of these areas, and in so doing acknowledge some important influences which have helped to shape my life. I begin with an account of some of the ways my family have contributed to my on-going rehabilitation and identity (re)construction.

My family's role in my identity (re)construction

I have been very lucky to have a close and supportive network of family. There is no doubt that my rehabilitation experiences have been guided by this support. In this section, I seek to highlight the way my family have shaped and continue to help in the on-going (re)construction of my identity following ABI, I include this section as recognition of the considerable impact this support has had upon my life. Much of what is included below stems from subsequent conversations with members of my family about their reaction to my injury and rehabilitation.

Throughout my adolescent years my family were supportive of my interest in healthcare. I was given financial as well as emotional support and encouragement to attend university to pursue a degree in physiotherapy. Although I was living and studying a considerable distance away from my family I was always afforded much support and encouragement. On 16th April 2003, my parents received a phone call from hospital to notify them that I had sustained a severe traumatic brain injury. After immediately rushing to be with me at this moment, my family have provided a constant source of support throughout my identity (re)construction.

In the very early stages of my rehabilitation (whilst I was in the acute hospital) there was a limited amount that my family could do; they were just happy to see me alive. Nevertheless I was shown constant support and encouragement to engage in the early activities of my rehabilitation. As I indicated earlier I was in the acute neurological department of the hospital for four weeks before I was transferred to a specialist neurological rehabilitation unit. The neurological rehabilitation unit is where much of my early rehabilitation took place. I was assigned a physiotherapist, an occupational therapist, a speech and language therapist as well as a team of nursing staff who were responsible for my day-to-day care needs. I largely felt that rather than acknowledging and utilising my familial support networks as sources of help within the rehabilitation process, my family were to a large extent excluded from my in-patient rehabilitation. I believe

this was in no small part due to a fear amongst rehabilitation staff that considering I was 21 years old and deemed an 'independent' adult, they had to accord to data protection laws. When viewed through a Braidottian or 'nomadic' lens, identity is not seen as an individual and isolated phenomenon. Rather identity is viewed as a concept that is comprised of many competing factors:

> 'The "self" is in fact a moveable assemblage within a common life space that the subject never masters or possesses, but merely inhabits, crosses, always in a community, a pack, a group, or cluster' (Braidotti 2011b: 331-2).

When applied to rehabilitation/identity (re)construction after ABI, the ABI survivor as 'the self' is conceptualised as a 'moveable assemblage' which is always part of 'a community, a pack, a group, or cluster'. Therefore the ABI survivor is no longer seen as a static, single figure, but rather is co-dependent on other parts of its support network, such as family.

The exclusion of my family from many of my early rehabilitative activities did not stop them from understandably delving toward my clinical case file and the beginning of each visit. As well as experiencing this myself, I noticed that almost without exception husbands, wives, mothers, fathers and so on would come to visit their loved ones within the rehabilitation unit, and immediately scramble to the folder at the bottom of the bed containing the multidisciplinary

notes to see how their family member had 'got on' in their therapy sessions that day. Of course, medical records of any person should be treated with the utmost respect for confidentiality. However, it is my contention that families can provide a great deal of support for people who enter rehabilitation for a vast number of reasons. Despite this in my experience family were involved in major 'case conferences' discussing my overall progression, but were excluded from day to day treatment sessions. In denying the influence of outside support networks, perhaps my rehabilitation professionals were repudiating the existence of a vital source of insight.

After my discharge from inpatient neurological rehabilitation my family continued to play a key role in my informal rehabilitation. I was encouraged to fully engage with all of the activities that I feel have aided my rehabilitation from that day to this. This has involved not least meeting my personal care needs; emotionally supporting me in all my academic pursuits; and helping me out financially and so on. In later years, this has also involved providing physical support and care to enable me to live in my own house; and driving me to various conferences and seminars to name but a few things.

Thus far, the above narrative seems to be one of dependence. This may seem to create the false impression of a binary relationship between care providers (my family) and care receiver (me). Although

I am a person who has sustained ABI, I have also been a source of support to my family. Before my accident I was able to provide an important source of support to my family. For example, shortly before my accident, my brother moved house and I was able to help carrying furniture into his new house. Since my accident I have been unable to help with these sorts of tasks. Importantly however, since my accident, there are a number of ways that my family view me as an important source of support and help. I am very proud of this. The only difference is the types of activities that I can perform. For example, I now drive a car, something that I was unable to do before the accident. I am quite frequently asked to help out members of my family to give them lifts. It may seem trivial, but I really appreciate the way that I am seen as a person who is able to provide help. Moreover, I also am able to be a source of emotional help to my family. Similarly the times that I able to be of some of emotional help are extremely rewarding to me.

My family have played a key role in my life and my on-going rehabilitation, both in the way they have provided support to me and importantly in situations (particularly after my accident) where they have encouraged me to be a source of support to others. In short they have played a vital role in my identity (re)construction. I now discuss the role of my friends over the years since my ABI.

The role of my friends in my identity (re)construction

Once again I have been lucky in that I was blessed with a group of supportive and encouraging friends who knew me before the accident. Since my ABI, the friends that knew me before have been keen to help me in any way they could with my rehabilitation. I have also made a great deal of new friends since my ABI. I often visit pubs and bars with my friends (with those I met both before and after my accident), and almost without exception they go out of their way to find me a seat. During the time I spend there, I talk, socialise and all the time, I am contributing to my on-going rehabilitation in diverse and 'untraditional' spaces and environments. It would be impossible for these important 'rehabilitative' experiences to be incorporated into any short-term rehabilitation framework, as my capacity to engage in such activities was unknown.

In recent years I have accrued more friends who know me more through my academic pursuits, and do not have any knowledge of me pre- brain injury. This for me is interesting and important, in so far as it neatly demonstrates the way that life is a fluid entity which is free to develop and change along with the passing of time. The support of my friends has been an important constant throughout my life including throughout my rehabilitation. During my rehabilitation, at no time have rehabilitation professionals sought to engage with me regarding the important role friendship would play in both my initial

and long term rehabilitation. Just as with my family, some of the moments that have given me the most satisfaction are those which I am able to be of some help to my friends. Helping others is very important to me as an ABI survivor, as it provides me with an immeasurable amount of satisfaction that I am not always a burden on my friends; rather in many situations we are able to have reciprocal relationships.

The situations where I am able to provide support to my friends, whether it is emotional support or physical support exemplify the way that reciprocity is a feature of such relationships. Within traditional, medically orientated discourses regarding ABI survivors, rather than highlighting reciprocity, the ABI survivor seems to be always the person who is in receipt of care rather than the care provider. The failure to recognise the reciprocity of these relationships adds to a conceptualisation of ABI survivors and indeed all disabled people as dependent, needy and passive (Watson et al. 2004). The way I have been able to provide support to my friends has been and continues to be a vital part of my identity (re)construction. I have discussed the role of other people in my rehabilitation and identity (re)construction. I now explore some of my rehabilitative experiences as they relate to non-organic objects.

The role of my car in my identity (re)construction

Due to my multiple impairments, I qualify for Disability Living Allowance, which is a state awarded financial benefit, which can in part mean that a car is provided to maximise my mobility. At the time of my inpatient rehabilitation, I could not drive and my ability to be able to drive in the future was under considerable doubt. However, since passing my driving test in 2005, I have been provided with a car which enabled me to travel mainly short distances to access local amenities and attend the local university for lectures and seminars. The amount of driving I do now has considerably increased due to the increase in my social networks and decrease in the effects of my impairments such as fatigue. During my time as a driver, I have been able to continue my informal rehabilitation by being able to foster my social networks, attend the local university, socialise and so on. These activities have played a vital role within this continuing rehabilitation. As I have mentioned above, these activities could not have been foreseen during my initial rehabilitation. A 'rhizomatic' and 'nomadic' rehabilitation would allow for the unforeseeable events of the future and at the same time recognise the importance of non-organic objects such as cars in the (re)construction of identity. For Braidotti (2011b: 353):

> 'Deleuze dissolves and regrounds the subject into an ecophilosophy of multiple belongings. This takes the form of a strong emphasis on the prehuman or even nonhuman elements that compose the web of forces, intensities, and

> encounters that contribute to the making of nomadic subjectivity' (Braidotti 2011b: 353).

In terms of my identity (re)construction, a 'rhizomatic' and 'nomadic' rehabilitation would place greater emphasis on the future and recognise the uncertainty of future activities including the role that 'nonhuman' objects such as cars play in the (re)construction of identity.

The role of my interests in my identity (re)construction - Football

For the whole of my life, I have been a keen supporter of the local football club. However, after leaving inpatient rehabilitation in late 2003, my interest has grown considerably. I now go to watch every home game of my local team with very few exceptions. However crucially, upon reflection I don't think the football matters so much. Much of the benefit is to be found in the way that I am able to socialise with friends and family, and ultimately continue my integration back into society.

My attendance at these matches was even more important during the first few years following my discharge from the inpatient rehabilitation unit, as my opportunities for social interaction were limited. I recall that before matches, when taking my seat in the stadium I used to try walking up the small number of steps without the physical support of my father, trying desperately to negotiate the

steps without too much of a 'wobble'. I remember proudly standing next to my seat when I had achieved this feat, and conversely cowering into my seat when I was less successful. For me, this provides yet further evidence that suggests the exploration of the every-day (seemingly mundane) (rehabilitative) activities of others should be enacted. To this day I believe that my attendance at these matches is an important part of my identity (re)construction. My rehabilitation was not a fixed and static notion that only occurred in fixed spaces, but rather is an on-going part of my life which takes place in all manner of different spaces and environments including the local football stadium.

Me as a young (male) adult

I am 31 year-old white British male, I am heterosexual, and do not have children. However, many of my fellow participants do have children. Some of them had already had children at the time of their ABI and some participants have had children since. With reference to the design of my research project, I decided to interview fellow brain injury survivors who are within six years of my own age and also male. I made this decision due to the way that I feel that this would result in participants seeming to have similar experiences to me in terms of life experience and family support (which is a commonly occurring theme throughout the thesis). This 'similarity' with the lives of my participants may make the assertions I am able to make during analysis all the more relevant (Bower et al. 2009; Patel et al.

2003; Ward et al. 2009). In summary, the decisions I made relating to participant recruitment were driven by my own age, gender, sexuality, ethnicity and so on. My recruitment procedures are explained in greater detail during the chapter that explores the methods I used to conduct the study.

When I sustained my acquired brain injury, I was 21 years of age. Together with the impairment- resultant difficulties that faced me, I was fortunate enough to be in a position where by the (re)consideration of an appropriate career path was also relevant. The additional complexity involved in recognising the way that individual needs may differ in neurological rehabilitation is noted in statutory guidelines (Department of Health 2005). These guidelines dictate the provision of rehabilitation services and the mention of the need to recognise individuality amongst ABI survivors lends further weight to the argument that suggests that in terms of my rehabilitation, it may have been more appropriate if services were provided to me depending on my specific needs. Together with considering career options, sustaining my injury at a relatively early juncture in my adulthood, meant that my social networks were not fully developed. An interesting facet of this debate is provided by analysing the way that I am treated by friends who knew me before the accident versus friends that know me only as the post-ABI Jonathan.

Broadly speaking, I think I am treated fairly similarly by people who knew me before and also those who did not. This however, does not account for the occasional stare, or refusal of entry into a pub due to the doorman confusing my speech impairment (expressive dysphasia) with intoxication. However, these occurrences are far outweighed by the helpful and understanding attitude of the general public. However, as I highlight later in this chapter, this may well be due to the imagery that my personhood provokes. At a very elementary level, when I am first encountered, I present as the archetypal 'disabled person'. I have fairly visible impairments, which seemed to conjure up notions of 'the poor young disabled person' who should be admired. My impairments seem to be considered as more 'serious' by non-disabled members of society, than those of a person with primarily cognitive impairments after brain injury. A 'rhizomatic' and 'nomadic' rehabilitation would allow for the contextualisation of impairment(s) into a (re)construction of identity.

It has been stated that regardless of our individual conceptions of impairments there exists a 'hierarchy of impairments' both within and outside of the disability movement (Deal 2003). Disability studies scholars have historically attempted to steer well clear of this notion, as drawing attention towards the heterogeneity of impairments, brings with it the risk of individualising the experience of disability (Barnes 2010; Barnes and Mercer 2004; Sherry 2006). Conversely, there have also been scholars to suggest it is simply unrealistic to silence the

issues surrounding embodiment and the lived experience of disability (Seymour 1998; Shakespeare 2006; Shilling 1997; Wendell 1996). Within research directly related to brain injury, the importance of the embodied experiences of research participants has received little attention (Sherry 2006; Lorenz 2010).

Mark Deal (2003) highlights the importance of impairment in identity. For Deal (2003) I would figure in a very different position on a 'hierarchy of impairments' to those who may have purely cognitive impairment(s). As Deal notes, this is important as those ranked differently by society may have wholly different social problems (Deal 2003). During informal interactions with prospective participants, it has been observable that many of these prospective participants have different (primarily cognitive) impairments. According to Deal (2003) this will mean that these participants may well have very different experiences of their identity (re)construction than me. The prospective participants have described some of the ways that they often feel they are charged by a disabling society as 'pretending' to be disabled and are treated entirely differently to myself. Throughout my day to day activities I seem to be accepted fairly well into society. When I go on to my local shop, almost invariably someone opens the door for me; when I enter a café alone, an attendant more often than not offers to bring my drink over to my table; when I get onto a bus, I often see the driver glancing in his mirror to make sure I am safely seated before continuing. The list is

endless. I am very grateful for this, but as I indicated earlier, this experience is not shared by everyone. As well as highlighting the individuality of the rehabilitation process and identity (re)construction after ABI, the way that the experiences of the participants may be completely different to mine could well have important methodological implications for my study. As such, I have not assumed that my identity (re)construction is going to be similar to that of the participants.

A personal web of rehabilitative sources

In the sections above I have described how my identity (re)construction has benefitted from the influence of my family; my friends; the influence of my car; and latterly the influence of personal interests in sports. I have drawn attention to these unique webs of support as they relate directly to the (re)construction of my identity after ABI. In an exploration of the influence of each of these on my rehabilitation and identity (re)construction has been and continues to be considerable. Furthermore, these experiences mark out the way that my rehabilitation and my identity (re)construction are unique to me. These experiences are unique to my life and cannot be replicated in a broad and all-encompassing way. As Tom Shakespeare (2006: 151) notes:

> '... People are different in their support needs, in their aspirations, and in their values... One size will not fit all.'

I would argue that these sources of support did/do not receive great attention in my rehabilitation. Of course, it would be impossible for many of these sources of support to be given full consideration during short-term rehabilitation, if uncertainty is an important characteristic of rehabilitation. However, these sources of support were and continue to be unacknowledged during my rehabilitation. If the importance of personal networks of support is acknowledged, then some of the basic aspects of rehabilitation such as the importance of achieving independence would appear to be called into serious question. Furthermore, the situations where I am able to be a source of support for others have been and continue to be a vital part of my rehabilitation. For now I wish to share some more of my rehabilitation experiences with the aim of providing a general impression of some of the ways I have had to integrate my impairments into my identity after ABI.

Personal adaptation

As much as I may attempt to down play the influence of my brain injury and the impairments I acquired as a result of it, I cannot refute the way in which I have had to adapt my life accordingly. Following my brain injury there are certain activities that I simply cannot enter into. However, at the same time are also activities that I can take part in but have to adapt my approach toward. To begin with a particularly

crude example, if I were to attempt to run down the street, I would fall over. Therefore, I do not run.

There are aspects of my body that are simply different now compared to how I have previously experienced them. It is on these elements that I intend to focus upon within this section. The first time I began to realise that I had to begin to plan ahead and adapt my actions due to my (new) corporeality was when I was in the neurological rehabilitation unit. I was frequently late for appointments for Physiotherapy, Occupational Therapy and Speech and Language Therapy. This was due to the fact that at the time, I used a wheelchair to mobilise. Quite simply I was not leaving enough time to get to the other side of the building where the therapy sessions took place. As soon as I began to get used to this, I began to mobilise with the aid of two crutches. The same thing happened again; I was always late. I was changing my embodied state faster than my brain could handle. I was not used to this.

My brain was used to attributing a certain amount of time to the task of mobilising a certain distance. This was something that had previously been fairly stable. My fluid and ever-changing embodied state had now complicated this previously mundane task. In this early phase of my rehabilitation, I needed extra time to ensure that I was mobilising safely. This example neatly exposes the way that my

rehabilitation needed to be viewed in a fluid manner and any approach which attempted to fix or statically conceive my needs, was wholly insufficient. To continue the above example, even to this day I often arrive early for appointments. I think this may be in part due to my increased sensitivity to arriving late that has been developed as a result of these experiences.

It is now over 10 years since my ABI and although my impairments are fairly stable, things such as tiredness etc. drastically affect the speed at which I am able to perform every-day activities. This has required constant reappraisal and reorganisation over the past 10 years or so since my injury. A 'rhizomatic' and 'nomadic' approach to rehabilitation and identity (re)construction would include such reappraisal and reorganisation in its wholly flexible approach to rehabilitative activities. I now draw this chapter to a close with a further discussion regarding the importance of subjectivity within my research.

'Truth seeking' or contingent knowledge? Exploring the (re)construction of my identity

When concerning rehabilitation and identity (re)construction the activities in my life can be divided into different stages. Firstly, there was the time I spent in early adulthood as a student Physiotherapist. As discussed above, my opinions regarding the value of knowledge

were largely grounded within a wholly objective, truth seeking framework. Secondly, there was a period of medical instability and early rehabilitation immediately after my accident. The third stage of my experiences of rehabilitation and identity (re)construction started when I was discharged from the inpatient rehabilitation unit and continue into the present and the unknowable future. They include all of my activities which have comprised the (re)construction of my identity. They include the every-day happenings involved in catching a train to conduct fieldwork for this thesis, together with the (planned) trips overseas to share my research findings. Rather than restricting rehabilitative activities to specific times, places and so on, a 'rhizomatic' and 'nomadic' vision of rehabilitation would allow for these diverse, unpredictable, subjective experiences to be 'imagined' in identity (re)construction

Conclusion

The conclusions I am able to draw from this study are gained from experiences as a trainee clinician, ABI survivor and social researcher. Each of these three strands of my subjectivity play an important role in any assertions I am able to make. Having said this it must be realised that most importantly I am a brain injury survivor who has obvious physical impairments. Despite any promotion of objective ideals, it is inevitable that my embodiment and the experiences that my body cannot hope to hide have had an effect upon the knowledge I

am able to produce in conducting this study. Rather than achieving a problematic ideal of objectivity, I want to use these experiences as an opportunity to demonstrate why it is that my body, my mind is indeed well placed to enact a research project exploring the (re)construction of identity after ABI. Secondly, making the decision to work with research participants prior to and during data collection dictates that I have had an unusual relationship with the people whose experiences I include. My relationship with the participants in my study is unusually close, and therefore requires a great deal of deconstruction in order to unpick some of the tensions and also to highlight some of the many opportunities such an approach poses. I turn to this task in more detail in the method/ology chapter.

To reiterate, within this research I seek to challenge research protocols which suggest that I am too intimately involved with the subject of neurological rehabilitation. These models may suggest that I cannot possibly hope to produce any objective 'un-biased truths' (Kaptchuk 2003) about the rehabilitation process. In response to this potential criticism, I highlight the celebration of the uniqueness of any person's life. Furthermore, I wish to dispute the existence of objective 'facts'. Within this research project, I am simply re-presenting some subjective opinions of the rehabilitation process and about life after brain injury from a *different* subjective position. Crucially, a sophisticated understanding of the virtues of subjectivity indicates that it is inevitable that these opinions differ from other (dominant) viewpoints, as they are drawn from a different standpoint; the

standpoint of the 'patient'. As I have demonstrated above, there are multitudes of divergent, and at times competing, ways of viewing any given subject in social life. Surely in order to maximise societal knowledge on a particular subject, views and opinions from many different perspectives should be invited and analysed. Thus, this chapter, in which I have shared my experiences of rehabilitation and identity (re)construction is an important component in this study

I have explored some important aspects of my personal biography. In doing so I have addressed the substantive questions upon which this study is based. I have discussed where my experiences of life have helped to (re)construct my identity as an ABI survivor; as a disabled person. Throughout this chapter I have sought to highlight the uniqueness of my experiences as an ABI survivor. Importantly in detailing my own experiences, as well as viewing them as unique I can analyse these and note any resonances with those of my participants. The way that my experiences compare with those of my participants will become particularly relevant when I discuss how I as an ABI survivor as well as a volunteer within an ABI support group have impacted on the project.

This chapter has sought to situate and contextualise my project. This chapter is not an attempt at narcissistic reflection, with the aim of achieving self-satisfaction (Letherby et al. 2012). Rather, following

Letherby et al. (2012) in highlighting the strength of my views towards subjectivity and competing opinions, it has seemed sensible for me to set out some of the experiences that have undoubtedly shaped my subjective opinions and driven the direction of this study. An analysis of my experiences indicates the fluidity of identity in the rehabilitation and identity (re)construction process. My experiences suggest that a 'rhizomatic' and 'nomadic' approach to rehabilitation and identity (re)construction that views identity in a fluid and malleable way is appropriate. Furthermore, this chapter has sought to demonstrate how this research has emerged from my unique experiences and in so doing has explored the possibilities that a thorough recognition of researcher subjectivity can stimulate.

Chapter 4 Capturing the (re)construction of identity after ABI: Method/ological considerations

Introduction

In this chapter I outline the ways in which I generated data for this thesis. I also explore the way that my identity as a researcher impacted on the project. I explore the method/ological issues that were relevant when capturing the complexity of life after ABI and providing thorough and rich answers to my research questions. In order to achieve this, I carried out qualitative, semi structured interviews with six brain injury survivors and thematically analysed (Braun and Clarke 2006, 2012) the resultant data.

Within literature that seeks to explore method/ological complexities of research, particularly that which makes explicit the way that the experiences of researchers has an influence over their research, it has been stated that perhaps researchers should talk of the method/ology of their project rather than method and methodology as somehow unconnected (Dumitrica 2010; Ellis and Berger 2001; Goodley et al 2004; Letherby 2002; Liamputtong 2007; Sikes 2004). Following these assertions, within this chapter I detail my method and discuss the methodological approach that I took to this thesis including a detailed discussion of my own role within the thesis. My research

questions are directed towards exploring how identity is (re)constructed after ABI. These questions have allowed me to begin to grapple with important issues which indicate the ways in which the participants draw meaning from their brain injury.

I worked as a volunteer in the organisation where I recruited five of the six participants for roughly one year. The sixth participant was a person who I met during the course of my own rehabilitation. This meant that I was reasonably familiar with all six participants prior to data collection. The inclusion of my own experiences, together with working alongside the participants meant that my identity was heavily invested in the study. Consequently I include a thorough investigation of my own influence on the study throughout this thesis.

This thesis moves away from understanding ABI solely through a description of medical impairments and instead moves towards an approach which captures the complexity of the identity (re)construction of ABI survivors. In my study I seek to present the 'lived experience' after brain injury. Rather than solely focusing on the meaning of a single experience (the brain injury) I explore many of the unique and intertwined facets of my participants' lives.

In order to thoroughly explore the experiences of my participants which relate to their overall identity (re)construction I have drawn direction from the qualitative method of life history interviewing. Within literature that explores the finer details of this method we are reminded by Roberts (2002) that there is no set method to the enacting of life history research. Indeed there are no set criteria which state that the interview must seek to represent a full life (Roberts 2002). Rather than seeking to represent a full version of a life, I seek to (re) present subjective life experiences from the perspective of an ABI survivor. This chapter explores the method/ological issues that I encountered in my study which investigates the day-to-day activities of ABI survivors. Within the empirical data I seek to represent life experiences following brain injury. My research seeks to further explore:

> '...the lived experience of individuals, the importance of multiple perspectives, the existence of context bound, constructed social realities, and the impact of the researcher on the research process' (Muller 1999: 223).

This assertion would seem to suggest that thoroughly investigating my role with/in the knowledge production is a key part of the study. Furthermore it has been stated that 'methods are never used by researchers in a theoretical vacuum' (Goodley et al. 2004: 96). In conducting a thorough investigation of my role in the research, I seek to make the process of knowledge production transparent (Harvey 2013; Letherby et al. 2012). Following Goodley et al. (2004) ensuring

that I include a thorough exploration of my approach to the research would seem to provide a clear background against which the theoretical perspective of the project can be viewed. My role as ABI survivor/ brain injury group volunteer /researcher seems to add to the exploration of the complexity of identity highlighting the multiple subject positions adopted within contemporary life (Goodley 2013; Mcguire 2010; Shildrick 2009). Moreover in drawing on my own experiences of life after brain injury, I seek to create a space where 'the richness, subtlety and complexity of researchers' own embodied thinking and being in the world can be told' (Davies and Gannon 2006:3).

In keeping with the theoretical approach of this thesis which seeks to investigate the complexity of identity, I explore the every-day (seemingly mundane) activities of my participants. I aim to present the experiences of my participants and explore how they negotiate their lives against the backdrop of the structures of the contemporary social world (Goodley et al 2004.).

In the following section of this chapter I discuss my approach as it compares to the approach similar researchers have taken to conducting research that seeks to explore the lives of disabled people with particular reference to those who have acquired an impairment which leads to 'sudden onset' disability. I then present a focussed

discussion of the ways that my study compares to other studies regarding ABI with particular reference to the subject of impairment. Following this discussion I describe the particulars of my research both in terms of the participants I chose to involve and also the design of my semi-structured interviews. The method of thematic analysis was used to make sense of the interview data. Thematic analysis has been described as a method of analysis which is widely used and theoretically flexible, yet its use is often poorly demarcated and rarely acknowledged (Braun and Clarke 2006: 77). In keeping with my commitment to maintaining the transparency of the way data was gathered for this thesis, I finish this chapter by thoroughly describing my approach to analysis.

Navigating the method: A different approach

Studies which seek to explore the complexity of identity of disabled people seem to favour narrative approaches to research (for example: Gelech and Dejardins 2011; Goodley et al 2004; Lorenz 2010; Medved and Brockmeir 2008; Sherry 2006; Smith and Sparkes 2008, 2011; Sparkes and Smith 2011; Tregaskis 2004). According to Sparkes and Smith (2008), sustaining a life-changing bodily event means that people often turn to narrative in order to make sense of the event. Thus it would follow that narratives may provide the most effective method of presenting the experiences of an individual who is trying to adapt their life to coincide with an unfamiliar corporeality.

Consequently Smith and Sparkes (2008) note that research carried out with disabled people is beginning to utilise the rich and diverse possibilities that exist when using participant experiences.

In seeking to explore the most effective way to re-present life after the sudden onset of disability, it can be observed that research often seeks to standardise 'typical' responses to phenomena. Within my study I do not want to standardise or generalise the accounts of the participants. Rather, I present their experience of brain injury and rehabilitation to promote an understanding of their uniqueness and their (re)construction of identity. I include further details of where 'types' of personal experiences have been observed to demonstrate how other research has sought to understand identity after sudden onset disability.

In their work with young sportsmen with spinal cord injuries (SCI) Smith and Sparkes (2008; 2011) and Sparkes and Smith (2011) observed distinct and identifiable responses amongst their participants. The 'type' of narrative accounts elicited depended upon the amount of time that has passed since the event. Sparkes and Smith (2011) and Smith and Sparkes (2011) observed three different 'types' of narrative that were drawn upon by their participants. These 'types' of narrative were first described and defined by Frank (1995). When recollecting events immediately following the injury, participants'

reported events in a chaotic manner, and due to the nature of the situation participants 'imagine life never getting better' (Smith and Sparkes 2011: 39).

A little after sustaining an injury another narrative form was observed was engaging with the experiences of participants. The second narrative format which Sparkes and Smith (2011) observed was the restitution narrative, which encapsulates the belief that the current form of embodiment is only temporary and in the future the previous state of embodiment will be reassumed. Sparkes and Smith (2011), observe that 'autobiographical time within this narrative structure operates within the philosophy of future' (Sparkes and Smith: 2011: 361) and the possibilities that the future may bring. Within this narrative, 'disability is seen as an aberration, a blip in the otherwise linear or normal passage of time' (Sparkes and Smith 2011: 362).

The third narrative form that was observed was that of the quest narrative. Rather than dwelling on the restrictions that disability and impairment may bring, these narrative accounts seem show how the reality of disability and impairment seem to have been accepted by an individual as an integral part of their life (Sparkes and Smith 2011). Within the three types of narrative accounts that were observed, the type of narrative account seemed to depend on the amount of time that had passed since the initial injury or catastrophic event.

> '... It is interesting to note that two of the men we interviewed, having lived within the restitution narrative for a number of years, gradually became drawn towards another narrative that allowed them to experience their body in very different ways' (Sparkes and Smith 2011).

Furthermore we are reminded, by Frank (1995) that these stories are not simply about bodies, but crucially narratives are also presented through our bodies. This assertion is important as the nature of embodiment at the time of the narrative account becomes pivotal. Put simply, the narrative accounts that people tell change over time. It is noted that the recognition of narrative 'stages' should not invite any judgement on the part of the listener (Frank 1998), and listeners should simply use this typology to make sense of the experiences of participants (Frank 1998). However, I did not take this approach in my research and preferred to make sense of the experiences of the participants through the analysis of themes. In a later section I will explore in detail my approach to analysing the interview data. Before this, I turn my attention to a discussion of examples of research concerning the lives of disabled people with a particular focus on the outcomes of such research.

Within much research that explores the lives of disabled people, there has historically been a call for such research to be 'emancipatory' (Barnes 2002; 2003) in nature (that is, to be driven by the acquisition of political rights for disabled people as a disadvantaged,

disenfranchised group). Indeed researchers have been provided with six core principles upon which to base their research (Barnes 2002; 2003). However, it has been noted that 'if research starts out with the pre-existing commitments to a particular understanding it will prevent reflexivity' (Watson 2012: 101). The predetermined and checklist-type of approach to 'emancipatory' research has received further criticism from those who believe that research should be allowed to develop without having to correspond to a pre-determined set of principles (Mercieca and Mercieca 2010; Mercieca 2011). Furthermore, if research is to be carried out in way that does not prejudge the lives of participants, it would follow that there should not be an all-encompassing set of directives. Relying on taken for granted assumptions and 'truths' regarding disabled people that conceptualises disabled people as a unified whole, would seem to indicate that it may be important to have disabled researchers that research disability. Indeed, research enacted within an emancipatory framework has been used to question the presence of non-disabled people in the disability movement and disability studies (Barnes 2003, 2008; Branfield 1998; Stone and Priestley 1996).

These assertions may be relevant when considering a view which suggests that researcher identity is important (Harvey 2013; Letherby et al. 2012). However, if the identity of researchers is made explicit and reflected on then the importance of the embodiment of the researcher may be questionable.

It has been noted that a detailed investigation of the identity of the researcher(s) necessitates a breaking of the 'orthodoxy of concealment' (Tregaskis 2004b: unpaginated) or put differently, demands a consideration of the implications of how researchers identify. The question of the position of non-disabled people within the disability movement was raised by Robert F. Drake (Drake 1997), and in a forthright manner, commented upon by Fran Branfield, in a later addition of the same journal (Branfield 1998). Within this response paper, Branfield suggests that non-disabled people 'who research and work in our area' do not belong there and 'their justifications [for being there] are doomed to failure' (Branfield 1998: 143). This reply provides an example of the difference between the political dimensions of disability and the quest to produce critically sound and transparent research. According to Branfield, there is no separation between the political dimensions of disability and disability as a critical and rigorous academic subject. Branfield sates that people 'who research and work in [this] area' should have personal experience of disability (Branfield 1998: 143). In further response to this debate, Paul Duckett (Duckett 1998) points out the fluid and malleable nature of identity. The way that 'there are as many differences within the disabled population as there are similarities' (Duckett 1998: 626) is employed to solidify Duckett's argument supporting the position of non-disabled people both within disability studies and the Disabled People's movement as a political organisation.

Crucially, the heterogeneity of the identity of disabled people is central to Duckett's argument. Furthermore, if disabled people are a heterogeneous 'group' of people of whom many do not wish to identify as disabled (Duckett 1998; Shakespeare 2006; Watson 2002) then perhaps this calls into question the relevance of whether a researcher (of disability) is disabled or not. If research is enacted according to a conceptual framework which is exploratory in nature and does not rely on oppositional traits to define identity, then perhaps researcher embodiment could be deemed irrelevant.

A discussion of researcher identity would seem to open up this issue to in-depth exploration. Notwithstanding the embodiment of the researcher, in striving to enact 'emancipation' the production of restrictive guidelines has been said to limit the opportunity for research to adapt and remain open to the possibilities which such research may enable (Mecieca 2011; Mercieca and Mercieca 2010). If research is to be judged solely on its ability to enact emancipation, then it would follow that a reflexive approach including a complex consideration of the way the research is produced, including a discussion of researcher impact, would be rendered unnecessary. Despite this a reflexive approach to researching disabled people's lives has been widely advocated (Danielli and Woodhams 2005; Goodley et al. 2004; Mecieca 2011; Mercieca and Mercieca 2010; Tregaskis 2004a, 2004b). One of the elements of reflexivity is a thorough investigation of the identity of the researcher(s). Therefore

research that is produced in strict accordance with Barnes' (2002, 2003) principles may oversee the importance of the investigation of methodological complexities of research that would enable a reflexive understanding of issues such as researcher identity.

When further interrogating the way research is being carried out, many scholars have noted that there has been a subtle shift in disability scholarship and there is huge capacity for a critical approach (Davis 2010; Goodley 2011; Goodley and Runswick-Cole 2010; Hughes 2009; Kumari Campbell 2009; Shakespeare 2010; Shildrick 2009, 2012). Indeed, some years ago it was observed that there were signs of 'stagnation in the promising field of disability studies' (Shakespeare 2005: 146). This would seem to suggest that the time for disability scholars to experiment with the possibilities of a maturing approach has arrived. In order to avoid any further stagnation, providing a sound and detailed explanation for the way that research is conducted (including an investigation of researcher impact) could well be important. Contemporary disability research seems to be emphasising the importance of critical and diverse thinking. It has been stated that contemporary disability research is unfolding in a way which will 'challenge not simply existing *doxa* about the nature of disability, but questions of embodiment, identity and agency as they affect all living beings'(emphasis in original) (Shildrick 2012: 30). As well as having important implications for the

type of research that is produced, this theoretical turn may well have an important effect on *how* such research is conducted.

Society is ever-changing and in no small part due to members of disability activist groups and the proliferation of disability studies as an academic discipline, the situation and level of oppression that disabled people now face is very different to that which was faced some three decades ago. A large amount of time has elapsed since 'disabled politics' began to be taken seriously, the situation has changed greatly and the time for fresh ideas may have emerged. A thorough investigation of what I did (the method), why I did it (the theoretical position) and the way I did it (the methodology) is directed towards the production of theoretically sound and transparent knowledge.

After engaging with literature regarding the choice of my method and exploring some common approaches to researching disability and impairment in general, I provide a critical discussion of previous studies concerning ABI.

Interviewing ABI survivors

In considering some of the complexities of interviewing people who have sustained a brain injury, one of the most enduring is the issue of fatigue (Gelech and Dejardins 2010; Lorenz 2010; Medved and Brockmeir 2008; Paterson and Scott- Findlay 2002; Sherry 2006).

Paterson and Scott-Findlay (2002) suggest that researchers' pay great attention to the sequencing and phrasing of interview questions during the pre-interview stage. Also important in planning the interview questions is the development of accurate lines of questioning which directly relate to the research questions (Paterson and Scott-Findlay 2002). As well as highlighting the potential challenge of fatigue, literature also warns that cognitive difficulties (such as memory recall) can lead to a difficulty in gaining rich and sufficiently comprehensive data (Paterson and Scott-Findlay 2002). However rather than suggesting strategies to overcome these complexities, such literature is directed towards drawing attention to the difficulties involved in researching the lives of ABI survivors. This provides an example of the impairment based, melancholic way that the lives of ABI survivors are commonly portrayed.

In opposition to this approach, when conducting his research with ABI survivors Sherry (2006) suggests that spending time with each individual and getting to know them helped him negate the 'problem' of obtaining sufficient data. Sherry (2006) reports that:

> 'By spending a long period of time with each individual... I was able to avoid the problems that some interviewers have reported about not getting sufficient information from their interviews with survivors' (Sherry 2006: 97).

Similarly in her study which investigated the lived experience of ABI, Lorenz (2010) observed that researching the lived experience with ABI survivors 'required personal contact' (Lorenz 2010:6) with ABI survivors themselves.

Furthermore it is noted by Sherry (2006) that spending time planning interviews and highlighting topics that are of interest, is important in research with ABI survivors. The use of techniques such as asking probing questions is suggested to ensure that sufficient experiences are discussed by participants. Indeed it has been stated that in all forms of medical qualitative research involving interviewing, questions should be asked in a clear, open ended and sensitive way, so that they are relevant and seem important to participants' (Britten 1995; Kvale 1996; Mason 2002) and provide opportunity for extensive responses. As well as taking great care over the planning of interview questions, Sherry (2006) also notes the importance of recruiting participants who are highly motivated to participate. This is also highlighted by Lorenz (2010). It would follow that if tiredness and maintenance of participant attention is a potential problem, then each participant should be committed to taking part in the interview. In the studies of both Sherry (2006) and Lorenz (2010) this was considered far more important than any desire to gain widely applicable or statistically significant results.

In an above section of this chapter, it can be observed that much research which explores the lives of people with severe ill health or a disability or conducted using narrative method/ological approaches. My research is similar in the way that it uses the narrative accounts of individual ABI survivors. However, much previous research seeks to explore the extent to which participants have 'come to terms' with their ill health/disability. Given that my research questions are exploratory in nature and seek to grapple with the complexities of the lives of my participants I do not seek to make any judgement as to what 'stage' of recovery/adjustment my participants may be in. Rather I seek to apply a contemporary social scientific framework in order to try and make sense of their lives as ABI survivors.

However, given the amount of literature that is concerned with maintaining the attention of, and avoiding fatigue when interviewing brain injury survivors (Gelech and Dejardins 2010; Lorenz 2010; Medved and Brockmeir 2008; Paterson and Scott- Findlay 2002; Sherry 2006), then close consideration would need to be given to the environment in which I conduct the interviews. Concerning the selection of a suitable interview environment, it can be observed in the academic literature that conducting research in a public location maximises the safety of both researcher (Morse 2007; Patterson, Gregory and Thorne 1998; Tourigny 1998) and research participant (Hayman et al. 2011; McCosker et al. 2001). This was therefore an important consideration in designing my study.

As well as influencing my choice of setting for the interviews, my engagement with the literature reflecting on research with brain injury survivors, directed my choice of method in other ways. For example, considering the potential impact of fatigue and attention (Gelech and Dejardins 2010; Lorenz 2010; Medved and Brockmeir 2008; Paterson and Scott- Findlay 2002; Sherry 2006) I thought that it would maximise the richness of my data if I limited the time frame of the interviews and instead conduct them over multiple days. This decision was made after examining much literature that exists on interviewing people both in a medical setting and also literature related to interviewing people who have sustained a brain injury. This was complemented by an interrogation of my own experiences and limitations, and carrying out a pilot interview.

As well as examining the literature pertaining to interview methods directly related to interviewing people who have sustained a brain injury, studies which have been conducted with people who are termed as having learning difficulties have also proved useful. I am particularly drawn to the assertion that states it is the competency of the method employed rather than the competency of the participants themselves that is revealed by research findings (Booth and Booth 1996; Gilbert 2004; Goodley 1996).

Conducting multiple interviews also means that if participants (and crucially I would also refer to myself in this) are having 'a bad day' or do not explain (or ask about) an experience particularly eloquently, conducting multiple interviews gave me a chance to revisit topics in the following interview. After spending a great deal of time thinking about the best way to access the experiences of my participants and enacting a pilot interview, I decided that it would be best to conduct two separate interviews with each participant, with the interviews lasting approximately 45 minutes each.

In my selection of participants, I have chosen to elicit the narrative accounts of people who are of a similar age to myself and are all male. All participants (including myself) are aged between 25 years and 33 years and sustained brain injuries within the past 3 to 15 years. This ensures a degree of consistency of experience, whilst at the same time ensuring each participant had at least three years in which to reflect upon and try to make some sense of their experiences and their new sense of corporeality. However, as I state below, I believe standardisation to be a problematic notion. I am uncomfortable at providing a completely static categorisation of the narrative accounts from the study. It is part of my role as a researcher to re-present narrative accounts produced from the research using the best possible framework. I feel that statically categorising these narratives into categories according to a fixed 'stage' in the rehabilitation process to be problematic. Rehabilitation means different things to different

people depending on many factors such as the heterogeneity of ABI. If researchers begin with the notion that each person is unique and special, it follows that will be an acceptance the participants may not react to any situation in 'common' ways. It is far better I contend to remain open to engage with the rich and thick descriptions of my participants lives (Mercieca and Mercieca 2010; Mercieca 2011) and respond to what is important to each participant regardless of the 'stage' of rehabilitation.

In terms of participant recruitment, following the success of similar projects which explored the experiences of ABI survivors (Lorenz 2010; Sherry 2006) I decided to make my choice of participants based on their willingness to participate in the study rather than trying to achieve a statistically representative sample. As I indicated above I decided to include my participants due to their demographic details such as age, gender and so on. I decided to include participants who were of a similar age to myself, and were all males. Given the way that I feel the researcher invests his/her identity into a research project; I thought that the inclusion of participants who have similar demographic details to me would allow me to thoroughly investigate my impact upon the study. Given the heterogeneity of brain injury (Fleminger and Ponsford 2005) and in my interest in long term identity (re)construction, including participants on the basis of the above information seemed to be appropriate in gaining a rich understanding of the (re)construction of identity after ABI.

The study achieved ethical clearance from both the Open University Human Participants Research Ethics Committee and the ethics committee for the voluntary organisation where I recruited participants. Through the distribution of an information sheet prior to the interviews the informed consent of all respondents was gained. This was made far easier because I already knew the prospective participants. In becoming a volunteer at the meetings, as well as also being a participant, I wanted the participants to view me as an ally (Goodley et al. 2004; Hayman et al. 2011; Heliker 2009; Morse 2007; Plummer 2001), thus easing any concerns. Furthermore, my presence at group meetings provided an opportunity for participants to discuss their concerns with me. The interviews were digitally recorded and transcribed by a third-party after being anonymised to insure optimal standards of confidentiality. Pseudonyms were used in the research to preserve the privacy of participants, with all names being treated as confidential (Morse 2007). However, as has occurred in similar studies (Stewart 2014) there were certain participants who did not want their names to be treated confidentially. As the participants were recruited from the same support group, identifying some of the participants could breach the confidentiality of all participants. Therefore the use of pseudonyms was necessary. This was explained to participants before the interviews. Participants were then encouraged to suggest relevant pseudonyms.

I now take the opportunity to introduce the participants. Given my commitment to 'theorised subjectivity' (Letherby et 2012: 79), as being '... a reflexive approach that acknowledges the significance of both intellectual and personal auto/biography of *researchers* (chapter three) and of *respondents*' (Letherby et al.: 90) (my emphasis), it would be sensible to introduce the participants. The introduction to the participants includes direct speech from the participants themselves. I have included these excerpts to highlight the way that it is through the experiences of the participants, that an understanding of identity (re)construction after ABI is gained.

An introduction to the participants

This section provides an introduction to each of the six participants in the study and thus begins the process of exploring their identity (re)construction after their brain injury. Much of these introductions are presented through the experiences of the participants. Therefore, within this section I seek to demonstrate the interests of the participants (Lorenz 2010; Sherry 2006; Stewart 2014) rather than encouraging an identification of the participants through their various impairments.

Sam

Sam was 29 years old at the time of the interviews. He sustained a traumatic brain injury at the age of 20. He was unemployed and worked voluntarily, on a part-time basis at the Citizens Advice Bureau. Sam has two children who were both born after his ABI and lives with them and his fiancée. Sam was not a member of the support group. Sam was originally intended to be the pilot interviewee. However, due to the success of the interview he was included in the overall study.

In terms of his hobbies pre and post ABI, Sam talked of how he used to enjoy cycling, but following his ABI and other impairments following the accident, he no longer was interested in pursuing this activity. Instead of enjoying sports such as cycling Sam now prefers spending time with his family and writing.

> "...I used to love cycling before my accident actually; I was cycling all the time. I had a drop handle bar racer, so I had proper pleats and clip in shoes, and I was really quite good... As well as having a head injury, I broke my knee in my accident. When I went home after leaving hospital, I was no longer interested in cycling in the same way... I sold my bike in the end because it hurts my knees..."

Sam repeatedly mentioned his love of driving. His ability to drive for long periods of time was reduced by his brain injury. Crucially however, Sam did not talk of his head injury and his tiredness being

an absolute barrier to his driving. Rather Sam discussed the need to monitor his level of tiredness:

> "...I do really enjoy driving. I cannot manage it for too long though because my attention goes... because my attention, I've got quite a low attention span, so I get tired really easily, so I can't drive all the time. I tend to only drive for a relatively short time..."

Sam was keen to talk about his experiences of travel and how his brain injury has helped to shape those experiences. Sam commented:

> "I don't like planes, I have only been on a plane once and that was after my accident and I really didn't like it, it was really claustrophobic, I really didn't like it, it freaked me right out. It was like being trapped in a tin can, argh. That is one thing since my accident actually, claustrophobia, I get really tense, even when I am putting a jumper on I get really, really edgy. If I have got a t-shirt on and I put a jumper over my t-shirt and my t-shirt is all scuffed up, I can't stand it, it is a bit like claustrophobia that but I am really claustrophobic now, I don't like tight spaces."

Sam is currently unemployed. Relatively soon after his injury, Sam had tried to engage in study but found it rather difficult. He talked about these difficulties and how he eventually quit the course:

> "I went to sound engineering at college, I did that for nearly a year, and because of my memory I couldn't take it in, I wasn't keeping up with anybody, so I had to quit that. And I started it the following year, and I still couldn't take it in, because I'm not very good at absorbing information."

Sam referred to how he does "things differently now" when he talked of his everyday life.

> "I do, do things differently now, I think because originally when you're young you learn a certain way to do things. And then you lose that having a brain injury, and then you have to learn again, so then you get used to another way don't you?"

Eric

Eric was 32 years old at the time of the interviews. He sustained an ABI as a result of contracting Encephalitis at the age of 20. Despite having various periods of employment since his brain injury, he was unemployed at the time of the interview. He lived on his own in a rented flat and had family close by.

It has now been 12 years since Eric's ABI, and he was keen to talk about his hobbies. Eric talked of the enjoyment that he gains from "being outdoors, in the fresh air." In particular Eric mentioned his love of gardening and how he liked to help his dad look after and maintain his allotment.

> "...I do enjoy gardening. My Dad's got an allotment which I go over there and do bits and bobs. I do get tired easily and I get bored easily and my concentration is not always there sometimes. I've got low blood pressure, which, I can't bend or stand too long. But I try to do things. You get used to it really..."

In opposition to this, Eric also talked of some of the activities he is less keen to reengage in especially after his ABI. Eric discussed his experiences of reading after his ABI, Eric commented:

> "I don't really like reading much. I find it trouble to read, find it hard to read...it's really hard picking the words out and describing them."

In my discussions with Eric it became apparent that he too struggles with travel. This seemed to be an effective way of encapsulating how his ABI has changed his life:

> "...before the brain injury, I used to arrange holidays with no problem; I had no care in the world. Everything was all right. I didn't have to worry about crowdedness. I never even considered the noise. Don't worry about it. It's all right...It's a big thing now – it's a major thing. I really hate travelling. It's all the hustle and bustle of things and it is very frustrating, I find..."

Wayne

Wayne was 25 years old at the time of the interviews. He sustained a TBI as a result of a road traffic accident at the age of 18. Wayne had three part-time jobs two of which were voluntary. He lived with his parents and sister. Wayne was born in the north of England and moved to the south-west when he was at primary school. Wayne was a keen football fan and reported being a "huge Manchester United fan". Wayne experienced fairly debilitating periods of fatigue following his brain injury.

In terms of his hobbies, Wayne referred to his love of socialising.

Wayne commented:

> "I absolutely love being out and about visiting with family and friends. I am always happy when I'm with other people."

Largely due to effects of his fatigue, Wayne discussed the importance of being organised. He was particularly eager to discuss his routines.

> "...Well to be quite honest with you I... before my accident and stuff like that I just used to get out of bed whatever yes, but now it's very important to me to be very organised because I know that I am not the quickest guy, and I get tired easily so I have got to organise myself. Every night before I go to bed if I have got work I will pre lay out my clothes you know, boxers, socks, trousers and shoes, you now my bags packed. Do you know what I mean? My lunch is in the fridge done you know, so I am not rushing around because I go to work. Like when I go to work I turn up an hour and a half early because I know that the buses can be a bit late and I take work very seriously you know... I like to be there early at work and I always start work fifteen minutes early you know because I like to know what I am doing, so I take it extremely seriously..."

One activity that he talked about as posing particular difficulty was that of travel. Wayne commented:

> "...I am not that good at travelling; I find it really hard... I find it exhausting...It just wears me out. It just completely wears me out..."

Wayne was also keen to talk of his views about the way he presents himself to others. Wayne says:

> "...I don't change for anybody, what you see is what you get, you know. I don't really care what anybody thinks. I don't change around my family. I don't change around my mates. I don't change in here..."

Rob

Rob was 33 years old. He sustained his brain injury as a result of having a brain tumour at the age of 20. Rob had a part-time job in a local supermarket. He lived in a rented flat with a friend. Rob was born in and attended school in Malawi in south east Africa due to his father's job. Rob and the family moved back to the UK after Rob's schooling had finished. Before his ABI, Rob was a chef. Since his ABI Rob "no longer cooks much" but says "this is something I may come back to. Who knows?"

In a discussion with Rob about what he enjoyed doing in his spare time we began talking about his hobbies both before and after his ABI. Rob discussed the impact sport had and continues to have on his life. Before his injury, Rob swam at an international level. Since his injury, Rob has become a keen supporter of his local rugby team. Rob enjoys watching them play with his father, which he says provides him with opportunity to socialise. As well as watching the

local rugby team Rob mentioned that he likes to spend time reading books. Of his interests, Rob said:

> "...Well, when I- before my tumour I swam a lot. I swam for my country, I played tennis for my country – I was very sporty...Since the brain injury, I tend not to do that anymore because I find it difficult. I find it difficult because of my left-sided weakness...I don't really do much of that any more... It upsets me that I used to be able to do it but I can't do it to the standards that I was at before, but on the other hand I now have more time to do things like watch rugby with my dad and read books, I really enjoy reading specially books by Andy McNab..."

As well as talking at length about his hobbies pre and post ABI Rob also talked about how he and his friends have adapted the way they do things routinely to lessen the impact of his impairment:

> "...Say I was going to a club or a bar or going to the cinema and there were some steps – I need to be on the right-hand side to get up those stairs... I have learned to be on the right-hand side of my friends when there are stairs ahead... you get used to it after a while, it becomes easy..."

Rob spoke of how he has learned "to cope" with his impairments over the time since his ABI.

> "...Over the years, since my brain tumour, the cause of my left-side disability, I've come to terms with it... It makes me feel awkward, and why can they not just give you five minutes of their time to ask you what's wrong or maybe speak to you about your injury or why you're walking instead of- instead of staring at you and thinking you're not normal?.. I know

> people look at me and stare at me because I may walk funny, I don't really care though... in my own head, that's who I am now..."

Jason

Jason was 28 years old at the time of the interviews. He sustained a traumatic brain injury at the age of 25. Jason's brain injury was the result of a road traffic accident. At the time of the injury Jason was employed as a lorry driver. Jason was keen to re-enter the job market, but felt that he would have to change his career as driving long distances would no longer be suitable for him. He was unemployed at the time of the interviews, but in part-time training to become a gym instructor. Jason had two children, one was born after his ABI. He lived with his wife and two children in a small village.

In terms of his hobbies, Jason talked of how he used to enjoy taking part in a variety of very physical sporting activities such as boxing and cage fighting. Due to the effects of his impairment, and the risks associated with him sustaining a blow to the head, he no longer is able to take part in such activities.

> "After my brain injury, I was told that probably wasn't a good idea to carry on with sports like boxing or cage fighting".

However, Jason spoke of how he has continued his interest in exercising in the gym following his ABI. He described why he still enjoys going to the gym:

> "... I still like going to the gym and find it really useful. It's strange, some days I get mood swings. I can spot the signs... I like going to the gym to let my aggression out... that really helps..."

Jason also described how he is able to spend more time with his young children since his ABI:

> "I walk my daughter to school every day, she's just started this year... I never thought I'd have the time to do stuff like that".

Karl

Karl was 32 years old at the time of the interviews. Karl sustained a stroke at the age of 29. Prior to his ABI he was an engineer and built parts for aeroplanes. Karl reported receiving a pay-out from a critical illness insurance policy shortly after his ABI. He was unemployed and not seeking work at the time of the interviews, but was considering the possibility of starting some voluntary work in the future. He had two children, one of which was born after his ABI. He lived with his wife and two children.

Karl talked about the devastating impact he felt in the initial period following his injury. He then began to compare this to he feels now:

> "There is nothing harder than having a critical illness. For anything. Cancer, anything. But things like your brain. It robs you of what you were and you become somebody new and you-now, you knew what that person was like before and you've now got to learn what the person is like after. 29 years old. 29 years of finding out who I was, and it was all taken away overnight, all gone in one hit... But life moves on, things change".

Karl talked of his enjoyment he gained from spending time with his young family.

> "I love spending time at home... Doing house work, cooking family meals I love it all".

During our conversations, Karl made great reference to the importance of routine in his life. In particular he discussed how he adapts his routine on a daily basis to restrict the impact of his impairments, such as fatigue:

> "So if I'm tired then obviously I just need to go to bed early and there's no point fighting the tiredness, because there's nothing worse in this world than feeling tired, so if it meant I was going to bed at 5.00 I was going to bed at 5.00. If I slept then I needed that sleep."

Karl also explained how having a strict routine can help negate the impact of his memory impairment:

> "...I wake up every day and the first thing I do is to always take my tablets... If I didn't do this straight away, I might wake up, go for my shower, get out of the shower, and then I might look at the tablet box and think, "Have I taken that or haven't I taken it?" whereas I know that I get up and the first thing I do is walk to the kitchen and then take my tablets... I know every time that I've got out of bed, I've walked to the kitchen and then I get my tablets. I never forget my tablets ..."

In this section I have provided an introduction to the participants. Much of these introductions are comprised of material spoken by the participants themselves. This is intended to demonstrate the competencies of the various people whilst highlighting the way the interviews were carried out in a nuanced and individual basis according the experiences the participants were keen to share. After briefly introducing each of the participants, I now return to a discussion of the construction of the interviews.

Designing the interviews

Considering the way I could maximise the richness of my data, together with the possible impact of participant fatigue, thoroughly piloting the interview schedule allowed me to give great consideration to the questions I wished to ask the participants (Sampson 2004). In conjunction with becoming familiar with prospective participants, this period of consideration in the planning phase of my research was vital. Of course, my study has benefited greatly from me taking time

to thoroughly pilot the questions I wish to ask in the interviews. However, I cannot overstate the importance of my own experiences together with the familiarity with the interview setting that I have gained from volunteering. I was determined not to become subsumed into pathologising discourses regarding the lives of ABI survivors that I discussed earlier in this chapter. Instead I viewed it as my role as a researcher to negate the influence of these challenges in order to provide thorough and rich answers to my research questions. Although I did not develop a universal, rigid interview schedule, I developed many questions which I designed to use as 'probing questions' should the need to extrapolate more detailed answers from my participants arise. As well as helping me devise a rough interview guide. I have also critically examined the issues pertaining to the interview setting. I now take the opportunity to reflect upon this area of my research planning strategy.

As a person who has first-hand experience of sustaining a brain injury, I am aware of some limitations that exist relating to the environment or setting in which the interviews are conducted. As a result of the 'unusual' nature of my impairments following my traumatic brain injury, I have been asked to participate in a number of research studies. These studies have always been conducted within a medical framework and I have never been consulted on the design of any of these projects.

In conjunction with other aspects of planning the interviews, I feel that the design of my study has benefited greatly from including the opinions of prospective participants. This is yet another advantage to investing time in becoming more familiar with the setting and the life-worlds of ABI survivors. Informally consulting the people whose details fitted my inclusion criteria, was an important part of the planning phase of the interviews. Prospective participants all indicated that they would prefer me to conduct the interviews at the support group/centre as this would seem to provide the most appropriate and convenient setting. Somewhat conveniently there was an office room just outside the main recreation area for the centre. After consulting prospective participants and asking their opinions I chose to use this space to conduct the interviews as this would provide a quiet space that ensured that the attention of my participants would remain maximised throughout the interviews. This would also ensure that I could remain focused on the experiences of my participants and therefore provides the best possibility of producing rich data.

My choice of setting was also relevant in terms of safety. It has been observed in the literature that conducting research in the public location increases the safety of both the researcher (Morse 2007; Patterson, Gregory and Thorne 1998: Tourigny 1998) and research participants (Hayman et al 2011; McCosker et al. 2001). Considering these assertions, the choice of setting allowed both myself as well as participants to be in close proximity to sources of support should they

be needed. My focus on my own performance as interviewer together with my choice to consult potential participants prior to data collection was aimed at challenging the deficiency-stressing dominant discourse in research concerning ABI survivors. Furthermore, it has been stated that persons recovering from ABI are often unfortunate recipients of unethical practice (Collicutt McGrath 2007). I remain fully aware of this and ensured I was committed to showing *compassion* to my participants; *respecting* their views and opinions; and being *empathic* to their concerns throughout the interviews.

Given that I considered my identity to be of the utmost importance within project, I believe it follows that I should include an account of my role within the research. I turn to a discussion of my role in the research after a critical exploration of the value of subjectivity and objectivity within social research.

Subjectivity and objectivity

In a previous chapter I have explored my own experiences of rehabilitation to emphasise the way that this study is guided by the notion of subjectivity over that of objectivity. Within research there is much scepticism at the employment of opinions that are generated from those who are not in a neutral position. I suggest, in accordance with my theoretical beliefs that are further explored in other chapters,

that neutrality is an unrealistic position. I now discuss this little further below before expanding the debate concerning my position in the thesis.

I am an ABI survivor. The experiences that I have accrued in my own life dictate that for me, objectivity would be an impossible epistemological position in which to locate a study investigating identity after ABI. Instead of striving for a 'neutral', objective epistemological stance, I have decided to share my subjective experiences of ABI and explore the possibilities that discussion regarding my subjective experiences may stimulate. This approach is one that is endorsed by Letherby et al. (2012:130) when exploring the value of subjectivity within social research.

> '... We need to acknowledge and theorise the embodied experience of research during data collection and in analysis and with reference to funder/researcher/respondent roles and relationships and identities - including reference to the significance of class, 'race' and ethnicity, age, gender, dis/ability, dress, accent and that the social differences and the impact of this on the process and the product' (Letherby et al. 2012: 130)

However, the use of subjectivity in social research is not without its critics. For many, the avoidance of subjectivity within social research is deemed as necessary to the enactment of 'good' social research. For example, Jenkins asserts:

> 'If we are to make any plausible claim article to understand the human world, and if the understanding that we offer is to stand any chance of being accepted as non-partisan or unbiased, then it is vital that we make at least some attempt to be objective...' (Jenkins 2002: 8)

As I stated in the introduction to this thesis were it not for my experiences of brain injury, I would not now be in a position where I were researching it. Whilst I accept I should thoroughly investigate my theoretical position and critically examine that position, I do not believe I should banish these experiences from my identity in an attempt to achieve an unbiased position when researching ABI. Rather I choose to embrace these experiences and explore what possibilities these experiences may provide. Researching life after an ABI, allows me to view many of the experiences the participants accrue from a broadly similar perspective. I would argue that this affords me the privilege of thinking through and unpacking the meaning of these experiences with a greater degree of understanding.

In accordance with literature that warns of the pitfalls of researchers being too involved in a study, knowledge that is produced by a person who is intimately involved with a subject matter is also discouraged, since:

> '... if the researcher 'goes native' he or she will interpret events solely from the point of view of particular participants, taking over any biases that are built into their perspectives' Hammersely and Gomm 1997:1.8)

As I stated in the introduction I have embraced my 'biases' in this study and have used them to my advantage rather than trying to downplay their influence. I have stated throughout my thesis that it is my intention to explore the experiences of my participants; of ABI survivors. Being a researcher who has first-hand experience of my topic of investigation is important when analysing the data I have produced. Having first-hand experience of disabled embodiment together with consideration of my role as researcher, has offered me the opportunity to interrogate the meaning of experiences, and afforded me a critical reflexivity which is difficult to obtain without such first-hand experience.

Hammersely (2009) further elicits his suspicions of 'bias', especially when researching topics that researchers may be intimately involved in when he states that:

> '... (The) simultaneous attempt to produce knowledge and to bring about social change of some kind...is liable considerably to increase the danger of bias (Hammersely 2009: 7).

It is my intention within this thesis to explore the experiences of my participants. I have great concern in stating from the outset that my

research is enacted with the aim of stimulating social change, as this could be construed as a particularly arrogant stance to take as a researcher. Furthermore I do not believe that it is my role to judge whether my research could be used to bring about some kind of social change.

The experiences of brain injury survivors are often silenced (Sherry 2006). I take the stance that my fellow participants and I have important experiences that need to be heard, and it is my job as a researcher to create a forum for our experiences; for our stories to be heard. I simply want to enact an exploration of the experiences of ABI survivors as I feel it would add to the body of literature which seeks to understand the identity of ABI survivors and disabled people in general. Furthermore I believe that engaging with the experiences of ABI survivors could add to existing debates surrounding ABI and the neurological rehabilitation process after ABI. In short I believe that research that is produced from a position other than that of 'value free', 'neutrality' does not then automatically mean that the aims of the research are significantly altered. I have explored in great detail my role in the construction of data and in the way my experiences have influenced this construction.

My position as a fellow ABI survivor, as well as my decision to spend time volunteering in the support group prior to conducting the

interviews greatly informed my choice of methods. Following this debate concerning subjectivity and objectivity I now turn to a further explanation of my role in the research. This is particularly relevant considering that my third research question seeks to explore the ways in which my identity has impacted on the study.

My role: Insider/Outsider?

A unique aspect of my study is that I am a brain injury survivor. In addition to the above aims this thesis also seeks to explore the method/ological approach that I took to the research, considering my position as brain injury survivor. Within the larger aim of exploring identity (re)construction after ABI, this thesis seeks to explore:

- *In what ways has being an ABI survivor and volunteering in an ABI support group impacted on the research?*

Following the debate in the previous section, within this thesis I view the notion of objectivity to be unobtainable within my research. Rather than attempting to neutralise my influence over the research I seek to capitalise on my position in the study and seize the opportunity to comprehensively investigate the role of subjectivity in my research. This necessitates a thorough investigation of my subjective position within the research. In seeking to explore my role within the research I have engaged extensively with the range of

literature which discusses the complexities surrounding the use of the terms 'insider' and 'outsider' across a range of disciplines in the social sciences. Although I believe these terms to be problematic and unhelpful in research, there is no doubt that examining these notions in great detail has played a huge part in the formation of my research questions. Exploring the extent to which researchers impact on a study is a notion that is demanding far more attention within contemporary qualitative research (Harvey 2013; Letherby et al. 2012; Thompson and Gunter 2011).

I pay particular attention to an investigation of my role within research by considering the way in which I can consider myself to be an insider' or 'outsider' within this thesis. Although the use of these terms is not helpful, a consideration of whether I can, or indeed want to claim 'insider' status (Dwyer and Buckle 2009) has stimulated a great deal of internal reflection. Within this context, being an 'insider' is termed as 'sharing the characteristic, role, or experience under study with the participants' (Dwyer and Buckle 2009: 55) and seen in direct opposition to being an 'outsider' who is defined as being 'an outsider to the commonality shared by the participants' (Dwyer and Buckle 2009: 55). It may seem to follow then that being an ABI survivor and sharing the experience of sustaining ABI, would dictate that I can classify myself as an 'insider' in this research. However, despite being an ABI survivor who is studying ABI, I do not view this to inevitably be the case. Even upon initial reflection, this definition appears

problematic. Indeed I have already stated that in my study I wish to explore the complexities of brain injury through investigating the (re)construction of identity after ABI. Although all of my participants (and me as the researcher) have sustained a brain injury and share that facet of identity, this commonality (being a brain injury survivor), is not a universally defining factor in the experiences I wish to elicit. I have considered notions of researcher identity alongside contemporary theoretical assertions which state that our identities are made up of a multiplicity of factors, and who we are is constructed from a dynamic and constantly mobile interplay of these factors (Braidotti 2011a, 2011b; Delueze and Guattari 1987/2004).

Increasingly, researchers who conduct qualitative research are therefore urged to investigate the ways in which their ever mobile and dialogical identities may inform their research practice (Thompson and Gunter 2011). However, despite this urge to deconstruct and analyse researcher positionality in research, the inside/outside binary would appear to remain largely untroubled in many research projects (Harvey 2013; Thompson and Gunter 2011). The recognition of the complexity of identity has coincided with concerns being raised over whether any researcher could claim a singular, fixed and immobile researcher identity (Thompson and Gunter 2011). An acceptance of this would seem to trouble any fixed 'insider' versus 'outsider' description of my role in the study.

I was aware that the way that my identity impacted on the research process would start with the first impression that prospective participants gained from me. Given my commitment to investigating the way my own identity was influential in the research, it is important that I discuss the type of impression I was trying to create. I begin with an interrogation of my feelings regarding being introduced to prospective participants.

On my first day working as a volunteer, the manager of the organisation introduced me to group members as "Jon. A volunteer". I would follow this by describing that I was "volunteering in the organisation with a view to possibly carrying out some research in the near future". As I became more familiar with the group members, I began to question why I felt it was important to add the fact that I was a research student. At the time, I convinced myself that it was ethically more acceptable to describe my intentions from the outset. This may be the case but does not tell the whole story. Upon reflection, I think I was determined to make a point that I was not just a volunteer, but a researcher as well. It felt that I was trying to emphasise that I was from a professional community. This could be seen as an attempt to distance myself from the participants' in my study, by emphasising my ability to overcome the problems associated with ABI. This reaction is problematic as in my determination to be viewed as more than simply a volunteer, it could be argued that I was demonstrating an adherence to the (much criticised) notion that

disabled people should aim to overcome their impairment(s) and should try to 'fit in' with the workings of society (Barton and Oliver 1997; Campbell and Oliver 1996). After thoroughly interrogating my reasons for doing this and moreover considering the implications this could have in my research, I decided to avoid highlighting my difference from the participants and adopted a more subtle approach, where I would refer to my intentions in general conversation. The implications of initial identification were all the more important considering the complex issues of power relations that arise when researching ABI.

In order to further demonstrate how the insights related to researcher positioning have had a comprehensive, practical effect on my research, I wish to refer to my research diary and my experiences of doing my study. Following Letherby et al. (2012) as researchers we are urged to critically interrogate the embodied experience of data collection. Furthermore as it is observed by Stich et al. (2012), qualitative researchers should concern themselves with many issues pertaining to their appearance and how they present themselves prior to entering the field. As is demonstrated by the following extract from my research diary, this study was no different.

> *Research diary 2 August 2012*
>
> *It is the morning that I begin volunteering. I open my wardrobe. What do I wear? I am keen to create a professional impression. However,*

> *as I know too well, medical professionals have had a profound effect on these people's lives. I want to appear smart and respectable, but at the same time absolutely do not want to present myself in a way that may cause prospective participants to view me as yet another professional who wishes to peer inside their lives. I reach into my wardrobe...*

Although it may, at first, appear to be a trivial consideration, the issue of researcher dress is now attracting far more attention within qualitative research. This may well be due to the methodological complexities of research being explored in greater detail (Stich et al. 2012). As with many of the complexities regarding researcher identity, the issue of dress is comprehensively explored in the body of literature regarding educational research. The issue of researcher dress is important in the work of Bogden and Biklen (2007) who note the importance of researcher dress when they state that what one wears 'can say something to others about who and with whom you identify' (Bogden and Biklen 2007: 98). Meanwhile, Stich et al. (2012), also highlight the importance of clothing during the research process, when they report on the methodological complexity of their research in an urban school:

> '... the seemingly trivial decision on whether to dress more formally to align ourselves with teachers, staff, and administration, or more casually with the hope of building more open relationships with students, sits inside a much larger set of meanings... Just as students wear uniforms to mark their positions, adults are expected to present themselves as distinct from should students through more formal dress' (Stich et al. 2012: 466).

Interestingly, the seemingly mundane question of what to wear in a research situation appears to have transformed from a simple question regarding researcher appearance, to one that cannot be separated from the wider issue of power relations in research. Having given greater consideration to the seemingly mundane aspects of the research process, I follow Stich et al. (2012) when they state that:

> 'Conversations around such seemingly mundane aspects of the research process both jump-started our reflection on this set of issues and serve as a point of departure for us to question the larger complexities linked to research identities and positionality' (Stich et al. 2012: 466).

Following analysing the issue of dress thoroughly, I decided to appear smart but not markedly different to other group members and volunteers. I made this decision as this would ensure that I had a professional appearance, whilst not marking myself out as different from the other group members and volunteers. As I have stated above I was particularly aware of the balance of power between me and the participants in the study throughout. It is clear that power relations are indeed very important in any study regarding neurological rehabilitation or ABI. Previous research has often been enacted through a largely medical lens (Gelech and Dejardins 2011; Lorenz 2010; Sherry 2006; Sullivan 2005). In wishing my research to act as a departure from previous studies, it follows therefore, that within my research considerable attention was given to ensuring that I did not replicate the situation which results in the participants being subjected

to yet more judgmentalism from professionals (Sullivan 2005). Furthermore, much healthcare research that involves gaining the experiences and opinions of people who have experienced some kind of life changing illness has been carried out by the very people that provide healthcare services (Conneley 2002; Carolan 2003; Newbury 2011). I am not involved in any health care service provision and I was keen to make that absolutely clear to participants.

As well as recognising the importance of the way prospective participants viewed me, I was also aware of the advantages that could be gained by other people considering me to be an ABI survivor. Due to the nature of my impairment(s), it was reasonably clear to group members, fellow volunteers and members of staff that I had sustained a brain injury. Despite my initial clumsy attempts to identify myself as a researcher, it seemed to me that the way I was a fellow brain injury survivor gave me some sort of camaraderie with fellow members. Indeed this is reinforced in the work of Sherry (2006). As I have previously stated I too feel this may well have helped me integrate into the group, and therefore may have had an impact upon the richness of the data I was able to illicit. I once again refer to my research diary to demonstrate my integration.

Research diary 22 August 2012

Fifteen minutes before I am set to leave for the day, a group member asks if I would like a lift to the train station in his car. I gratefully accept. On the short journey to the train station I cannot help but think that this may well be a sign that my methodological approach to volunteer prior to data collection may be working. It could well be that I am being accepted into the group. I then wonder about the implications this has for the data I collect. Will this add to the richness of the experiences the participants' discuss? Just as I begin to ponder this question the journey is complete. I say my goodbye's and enter the station.

This occurrence seems to encapsulate how I may be in an advantageous position in trying to establish relationships with participants prior to data collection.

In another project which sought to explore identity after ABI, Sherry (2006) indicates how he felt being a fellow brain injury survivor may have helped him in data collection. Perhaps the same could apply to my study. However, this assertion must be viewed against the theoretical assertions above which indicates that we are all made up of multiple and ever-changing factors. Considering this, I believe that being a person who had also sustained a brain injury may well have helped initially. However, thinking I was in an environment where I belonged was no substitute for presenting myself with the utmost professionalism and treating participants with the respect they deserve.

In further discussion of my experience of the research during the data collection and analysis, at times I was a little troubled during the volunteering phase of my research. The 'typical' duties of the volunteer within the centre would include things such as making group members a drink or providing physical support during walking. Due to the nature of my physical impairments, I could not do this. This made me feel a little uneasy and even led to me questioning the usefulness of my presence at the centre at times. However, after a month or so of my volunteering at the centre, one of the group members began studying for an exam he was taking in human anatomy and physiology. When I was a physiotherapy student, I learned quite a lot about anatomy and physiology and I could still remember a fair amount of the answers to his questions. I spent a good deal of time working through his questions with him. This made me feel much more useful as a volunteer, and only served to reinforce the assertion that identity is comprised of many diverse factors.

Having sustained ABI, I am indelibly linked to the process of rehabilitation. As a result of this link, I have very strong views on the process of rehabilitation. However, I feel it important that I find a way to amalgamate the intertwining aspects of my identity as: a survivor of a brain injury; as a researcher; as volunteer; as Jonathan. As well as providing a stable base upon which to reflect on the data I collect, recognition of the multiple subject positions that I occupy during the research project provide other important advantages. The way that I

am able to elicit an exchange of ideas gives me an advantage in conducting this research as many of the participants may be expecting a researcher who is in some way tied to the medical aspects of the rehabilitation process to be interested in gaining their perspective on their rehabilitation. To reiterate I identify neither as an impartial 'objective' 'outsider', nor a bias-laden, all knowing 'insider'. I hope that embracing the multiple subject positions that I assume during the study, has added to my ability to present some of the complexities of life following brain injury.

Towards the end of my involvement within the support group I had to analyse the data that I had gained from the semi-structured interviews with participants. Following a call for the methods of analysis to be explored in detail (Braun and Clarke 2006), I now turn towards an exploration of the analysis of my data.

Analysis of the data: A Thematic analysis

In conducting the analysis of the interview data I used the qualitative method of thematic analysis indicated by Braun and Clarke (2006). Braun and Clarke assert that '(t)hematic analysis is a poorly demarcated, rarely-acknowledged, yet widely-used qualitative analytic method' Braun and Clarke 2006: 77). This assertion has provided the point of departure from which I conducted the analysis

of the semi-structured interviews within this thesis. Thematic analysis has been described as a theoretically flexible and widely used method of analysis (Braun and Clarke 2006). Due to the focus upon themes that emerged from the data, a thematic analysis approach is often considered as an offshoot of grounded theory, where broadly speaking the data is used to construct theory, rather than the gathering of data to support a pre-existing theory (Riessman 2008). Braun and Clarke (2006) argue that thematic analysis should be considered as a method itself. The ability for thematic analysis to support research from a number of epistemological and theoretical perspectives is considered to be crucial (Braun and Clarke 2006). My study is concerned with generating data to offer new theorisations of the lives of brain injury survivors. I use theoretical insights that are already in use but crucially the theories I use permit an understanding of the identity (re)construction of ABI survivors that have not previously been used for this purpose. I would argue therefore, that this thesis is substantively concerned with generating data to aid the construction of theoretical insights regarding the lives of ABI survivors.

In keeping with the exploratory nature of my research it has been stated that thematic analysis is directed towards the development of theories (Holloway and Todres 2003). For example, in the field of health care research thematic analysis has been used to investigate the role of performance feedback in nursing practice (Fereday and Muir-Cochrane 2006). Braun and Clarke's (2006) framework of thematic

analysis provided the backdrop for study that investigated clients' perspective of brain injury rehabilitation in a residential rehabilitation unit (Gill et al. 2012). The approach of thematic analysis was said to facilitate a detailed and nuanced comparison of participant experiences and how they may intertwine to enable an intricate investigation of the neurological rehabilitation process (Gill et al. 2012). In further describing how my data were analysed according to themes that occurred in the interviews, I now turn to a detailed description of the process of data analysis.

Analytical method meets theory: Thematic Analysis

My thesis seeks to explore identity following ABI and therefore contribute to the debate surrounding the identity of disabled people as well as unsettling some taken for granted assumptions in the neurological rehabilitation process after ABI. This was achieved by critically engaging with the accounts of ABI survivors. In my analysis, I engage with aspects of critical social scientific theory to make sense of the experiences of my participants. Engaging with critical social scientific theory has enabled me to retain an exploratory approach to research which seeks to ask questions rather than rely on dominant portrayals of 'truths' within the lives of ABI survivors. The way in that I draw on personal accounts may seem to indicate a more phenomenological, realist approach. However, I am not suggesting that the accounts of participants are the only important accounts

regarding rehabilitation. Having said this, it has been stated that the voice of the survivor is often missing in debates regarding ABI (Lorenz 2010; Sherry 2006). The way that this thesis seeks to investigate the long term implications of ABI and rehabilitation from the perspectives of ABI survivors is important but should be considered as simply one perspective. Along with the perspective of the survivor, there is also that of the neurologist, rehabilitation professional, nurse, family member of the survivor and so on. This thesis seeks to contribute to the filling of this space by interrogating ABI and rehabilitation from a different perspective. The data that I present is driven by the need to answer my research questions; to explore identity after ABI from a survivor's perspective rather than any attempt to provide a holistic 'neutral' account of identity (re)construction after ABI.

A step-by-step guide to the construction of data chapters

Braun and Clarke (2006) suggest a methodical way of conducting data analysis which uses thematic analysis. I now turn to these guidelines and demonstrate how I approached the task of analysing the data.

Rather than a linear process, analysis was enacted in a far more recursive way. During analysis, I moved backwards and forwards throughout the phases that I will outline. For example, writing the data chapters was enacted during the whole process rather than being

an activity exclusively saved until the end of the analysis. I noted down ideas and possible coding frames early on and then moulded these into subtitles for the chapters as they started to take shape. As I outlined above, and is suggested by Tuckett (2005), my analysis rather than being purely inductive in nature was informed by my engagement with the literature and by my own experiences. The literature therefore enhanced my analysis in making me familiar with some important debates regarding people who have sustained ABI and disabled people in general. Familiarising myself with these debates undoubtedly sensitised me to the presence of these issues in my data. I am in no doubt that my critical eye was further sharpened by my personal experience of being a brain injured person and by the insights I gained through my voluntary work.

Initial familiarisation with the data

I was given financial support to have the interviews transcribed. Although this was without doubt a considerable help in terms of saving time, it meant that I would not have the same degree of familiarisation with the data than if had I been responsible for transcribing the data. Thus, before the interviews were transcribed I ensured that I listened to interviews several times. I feel this aided my understanding of the data greatly. Firstly this provided an opportunity for me to initially familiarise myself with the contents of the interviews. Furthermore, rather than simply reading the transcripts, I

was able to listen to the words of participants and take note of patterns of intonation etc. This without doubt informed my initial analysis as I was able to observe aspects that seemed particularly important to participants. This also helped me when checking the content of the transcribed data against the original audio recordings to ensure they had been transcribed accurately.

Code generation

As I have stated above, I began to notice interesting elements of the raw interview data that seemed to capture my attention. These interesting 'chunks' of interview data were then noted and compared to both my autobiographical experiences of rehabilitation and the general impression that I had gained through becoming familiar with the lives of my participants, which was aided by referring to my field notes. I then referred back to the literature to ensure that these trends in the data seemed to be centred on an interesting debate. When I received the transcriptions, I collated individual chunks of data into separate computer files. During this time I continued to listen to the original audio recordings of the interviews. In listening to the audio recordings, I was able to enhance my analysis by observing the particular context in which participants spoke about a given topic. The loss of the context of participant utterings during analysis is a common criticism of the coding process within qualitative research (Bryman 2001) and one which I was able to limit.

Due to being familiar with the literature on brain injury and the lives of disabled people prior to coding, there is no doubt that during analysis my critical eye was drawn to certain aspects of my data that seemed to collaborate with interesting debates in the literature. This is why I believe my analysis was theoretically driven rather than purely inductive in nature. This is when the major themes in my dataset began to be constructed.

Sorting codes into larger themes

In gathering similar 'chunks' of data into separate computer files, I had already began the process of generating themes. The theme generation process was aided by a more thorough engagement with the literature that each chunk of data seemed to be relevant to. This process involved a constant referral between raw interview data, biographical data, observations and the literature pertaining to people who have sustained ABI/literature related to the lives of disabled people. At this stage I began to consider the chunks of data that would comprise each of my data chapters. To aid this process, I continued my theme generation by creating 'mind maps' to help me to further sort out my coded data. These 'mind maps' included coded chunks of data that I had not managed to sort into a subtitled category, but seemed to be consistent with the overall theme. In creating these 'mind maps' I continued to refine the subtitles for each of the chapters and with constant referral between the data and the literature, I managed to think through how the data fitted into a specific subtitled

category within a theme. During the above steps the process of constructing overarching themes for my chapters was enacted.

Reviewing my themes

After sorting my data into overarching themes that would eventually comprise data chapters, I had to refine these themes. In addition to thoroughly engaging with literature that indicated the most effective way to employ thematic analysis, I was guided in these decisions by listening again to the audio data files to ensure contextual accuracy. I was reminded that each chunk of raw data could possibly be related to more than one theme and therefore appear in more than one chapter. All throughout the theme generation and refining process, I continued to read and listen to transcriptions/audio files to ensure that I was generating themes that would represent the data accurately. This involved a constant referral from raw data to individual chapters, to ensure that each topic in each theme appeared to form a coherent pattern. This involved refining topics in an organic, on-going manner.

Going back to my research questions

After identifying and refining each theme, I provided a detailed explanation of why the data comprising the theme answered one of my research questions. Therefore, for each theme I wrote a detailed analytical account of why the raw data comprising the theme/chapter

was of particular interest, and how it fitted into my overall thesis by relating to my research questions. I had to achieve a balance between not enforcing my own views on the data and at the same time demonstrating how each theme contributed to the overall 'story' I wanted to tell in my thesis.

Naming themes and topics within themes

Deciding on naming individual topics within themes, was made considerably easier by thoroughly considering the meaning of each topic and how they related to the larger theme or chapter within which they were placed. I used a variety of techniques for choosing a name for each topic. Occasionally I used verbatim extracts from the data to name a topic. In these cases, I decided that the verbatim quotes summed up the essence of the topic in a far more succinct, punchy and effective way than any subtitle I could think of. Thinking through how each theme/chapter contributed to the overall tone of the thesis, and how this collaborated with my research questions (the step above) undoubtedly facilitated the choice of name for each chapter. In addition, the naming of each chapter was undoubtedly made easier in referring to participants talk. With this in mind, I re-read each chapter a number of times before deciding on a final name.

Thematic analysis is an approach which draws common themes across a number of cases. This together with its theoretical flexibility indicates that thematic analysis is an analytical approach that is most appropriate to analyse my data and provide answers to my research questions. Given Braun and Clarke's (2006) observations regarding the lack of transparency in much research which uses thematic analysis, I have sought to describe my approach to analysis in some detail. I conclude this chapter with an account of my overall method/ological approach and how this method/ological approach enabled me to provide rich and detailed answers to my research questions.

Conclusion

Within this chapter I have demonstrated how my method/ological approach has been thoughtfully constructed in order to provide rich and full answers to my research questions. I began this chapter with a discussion of the ways in which research pertaining to disabled people and ABI survivors has been conducted. I have discussed research with disabled people as it relates to common frameworks. Following the above discussion, I moved on to outline some of the finer details of the method of the study including issues relating to the ethics of researching with ABI survivors. In the latter part of the chapter I have provided a critical account of my role in the research together with a discussion detailing how I analysed the resultant data.

Discussion of the method I used to enact the interviews, together with an interrogation of some of the ways in which my own identity has impacted on the research is most relevant, especially when considering my unusual epistemological position (being a trainee clinician, turned ABI survivor, turned ABI researcher). In addition, I considered that it was useful to provide a fairly detailed account of my method of analysis. This was especially relevant considering the way that thematic analysis is widely used yet rarely discussed in detail in research literature (Braun and Clarke 2006). My method/ological approach has enabled me to provide rich and detailed accounts regarding the (re)construction identity of ABI survivors and demonstrated my unique contribution to literature regarding the identity of ABI survivors and disabled people in general. In the following chapter, I explore the notions of dependence, independence and interdependence in the lives of the participants.

Chapter 5 Dependence, independence and interdependence in the lives of ABI survivors

Introduction

Within this chapter I seek to explore the lives of the participants as they relate to the notions of dependence, independence and interdependence. It has been noted that Western societies produce discourses which promote the idea of personal autonomy and independence (Gibson et al. 2012). Indeed, the realisation of independence has been highlighted as a key concept within neurological rehabilitation (Barnes 2003), and much of the focus of rehabilitation is directed at the achievement of independence. Following this, in this chapter, I present the experiences of the participants that relate to notions of dependence, independence and interdependence. This chapter seeks to investigate some of the ways in which the experiences of the participants can inform the existing literature regarding neurological rehabilitation following ABI. In terms of my research questions, investigating the notions of dependence, independence and interdependence within the lives of ABI survivors adds empirically to debates surrounding identity (re)construction after ABI and also contributes to an investigation of when, where and how rehabilitation after ABI takes place.

In the analysis of my data, it became apparent that the presence of other people or objects played a pivotal role in the participants' rehabilitation. Furthermore I will discuss below some of the ways in which my analysis of data provides examples where the realisation of complete autonomy and independence is often unrealistic for my participants. I explore the ways in which my participants are in(ter)dependent upon other people, environments and objects in their daily lives. This concept is one that is in play throughout the course of the participants' accounts of their rehabilitation. In keeping with the need to question dominant or taken for granted practices within rehabilitation (Gibson and Teachman 2012) I seek to establish how my analysis of the experiences of my participants highlights the relevance of the notions of dependence, independence and interdependence within their rehabilitative journeys. It should be noted that in this thesis I seek to adopt a critical approach through an engagement with critical social science which strays far away from seeing rehabilitation as a linear, chronological process, and rather views rehabilitation as a messy, less ordered phenomenon. However, for the purposes of the opening sections of this chapter I present the experiences of the participants in a chronological way. I detail participant experiences in such a manner as this is how my participants seemed to make sense of their experiences. Moreover, this linearity seemed to allow my participants to reflect and make sense of the notions of dependence, independence and interdependence, as it enabled them to frame their experiences in a

methodical way. Before I turn to the experiences of the participants, I now explore the relevance of viewing these experiences in a rhizomatic and nomadic way.

The relevance of a rhizomatic and nomadic framework to discussions of dependence, independence and interdependence

This chapter is concerned with the ways in which the experiences of ABI survivors can inform an understanding of identity (re)construction after ABI through analysis of the notions of dependence, independence and interdependence. I seek to make sense of the experiences of the participants by engaging with the theoretical assertions of Deleuze and Guattari (1987/2004) and Rosi Braidotti (1991, 2003, 2006, 2011a, 2011b, 2013).The relevance of a rhizomatic and nomadic framework is prompted by Deleuze and Guattari's questioning of the static human subject and reconfiguring a vision of life to encompass the notion of 'becoming'. This dynamic and wholly affirmative vision of life has been continued and brought into the contemporary arena through the work of Rosi Braidotti. If life is conceptualised as being in a perpetual state of transition, then static descriptions of what we may be at any one time become far less important than conceptualisations of what we could be. Life is considered a 'nomadic' existence whereby our experiences are embraced and said to play a crucial role in our lives as continuously developing human beings. This is captured by Deleuze and Gauttari when they state that:

> 'An organism that is deterratorialised in relation to the exterior necessarily reterratorialises on its interior milieus. A presumed fragment of embryo is deterratorialised when it changes thresholds or gradients, but is assigned a new role by the new surroundings.' (Deleuze and Guattari (1987/2004:60)

Within this constant development (or reterratorialisation) (Delueze and Guattari (1987/2004), we are encouraged to venture far away from our fate and stray into our imagined selves where the possibilities are limitless. The positivity that the idea of perpetual motion indicates has been built upon by Rosi Braidotti who refers to the potential of this mode of thought as serving to reconfigure a person as a:

> 'Spaciotemporal compound that frames the boundaries of the process of becoming this works by transforming negative into positive passions' (Braidoti 2011b: 314).

The 'transformation of negative into positive passions' is unpacked by an explanation which suggests:

> 'The practice of transforming negative into positive passions is the process of reintroducing time, movement, and transformation into a sifting enclosure saturated with unprocessed pain' (Braidoti 2011b: 314).

In other words a rhizomatic and nomadic framework allows an understanding of the lives of the participants which does not focus on what their bodies may lack at any given time. Braidotti builds upon

the idea of positivity and frames it in a rhizomatc and nomadic way still further by stating that the human subject is defined by:

> '...its interrelations to others in a rhizomatic manner that defies dualistic modes of opposition' (Braidotti 2011b: 311).

Therefore within this conceptual framework, notions which are in direct opposition to one another such as dependence/ independence become problematic. It is argued further by Braidotti, that contemporary life has led to a further blurring of 'the natural and cultural' (Braidotti 2013: 3) when she states that:

> 'The boundaries between the natural and the cultural have been displaced and to a large extent blurred by the effects of scientific and technological advances' (Braidotti 2013:3)

In relation to the theme of this chapter, this framework enables researchers, healthcare professionals and so on to think sophisticatedly about the issues of dependence, independence and interdependence in the lives of ABI survivors rather than relying on dominant ways of thinking which seem to unproblematically link dependence to notions of lack. According to a rhizomatic and nomadic conceptual framework, the role of giving and receiving care and support in the lives of ABI survivors is understood not as a way of achieving independence, but rather as a reciprocal and wholly fluid arrangement in which ABI survivors are actively engaged in. I now turn to the experiences of the participants.

Early interactions: the importance of support in early care

In the immediate aftermath of their brain injury the participants recalled that they were very dependent on the help and support of nursing staff. As well as highlighting the relevance of dependence and the importance of care, the following excerpts also portray some of the challenges that need to be addressed when interviewing participants who struggled to recall the events around the time of their brain injury (Paterson and Scott-Findlay 2002).

Eric's experience was very typical in the way that he both was heavily dependent on others and had difficulty recalling any detail regarding his stay in hospital. This is summed up by the following exchange:

Me: Can you talk a little about what happened straight after your brain injury?

Eric: Err, I don't really remember much...the total span was 7 weeks. That's from going into hospital with my problems and finding out I got Encephalitis, and then being discharged, so yes 7 weeks.

Me: Right okay can you tell me something about the things you did during those 7 weeks?

Eric: Erm, don't really remember much... erm, lying in bed for a lot, then I got physio to help me walk again. Err, I don't really remember much of those 7 weeks.

This excerpt demonstrates the way that Eric was heavily dependent upon the care of healthcare professionals in the immediate aftermath of his brain injury caused by his encephalitis. The way that he talks of "lying in bed a lot" and then having physiotherapy to help his mobilisation depicts such dependence upon health care professionals.

Eric was able to recall something from his early care that was relevant to how he felt completely dependent on the care of others at this time in his rehabilitation. Eric explained how a nurse accidentally dropped a tablet whilst giving it to him. Rather than discarding the tablet and giving him another, Eric described how the nurse simply wiped it in her uniform and then gave it back to him. At the time Eric understandably says he was "too ill to care really", but since has reflected upon this event and remembers it vividly:

> "It annoys me, I think it's a sign of neglect, I think it's a lot of problems in hospital really... they could do with much better cleaning and that. If you know the floor is dirty, you don't pick a tablet off the floor and give it to someone, you just, you get rid of it and get a fresh one, but they didn't... it's not right."

With reference to notions of dependence, independence and interdependence Eric's experience denotes the way that in the immediate aftermath of ABI, Eric was completely dependent upon the care of nursing staff. This demonstrates the way that the relationship between dependence, independence and interdependence should be

conceptualised as a continuum where at certain times dependence can be both inevitable and productive. In terms of identity (re)construction following ABI the events in the immediate aftermath of ABI, indicate the relevance of notions of independence since dependence upon others is accepted as necessary and preferable.

Sam also had great difficulty recalling events immediately after his ABI. Despite this, Sam highlights the importance of having family support at this time.

> "I can't really remember much about hospital... I had to start from scratch again, when I was in hospital... I lost my memory and all of that really, so I had to start again. And they had to teach me everything really, real basic skills that kids learn in primary school I had to learn in my 20's... Well also my family used to come and see me a lot... [Them] coming in made a difference actually... My family used to visit me every day that was a big thing"

As well as highlighting where Sam too finds recalling the immediate aftermath of his injury particularly difficult, Sam's experience demonstrates the way that he required quite considerable care from both health professionals particularly when he states that "they had to teach me everything really". Crucially Sam also talked of the positive impact of having family members visit him in hospital when he states: "them coming in made a big difference actually". When I analysed this statement with reference to the importance of dependence,

independence and interdependence this statement highlights Sam's feelings that his ABI was not something that he had to face by himself (independently), rather that he drew on the support of his family even at this early stage.

Similarly Jason had difficulties in recalling the events in the immediate aftermath of his brain injury.

> "Firstly, I was in hospital then I went home for a couple of weeks, then I went to a rehab unit for a couple of months, then I went home for Christmas and then I started getting better... Sorry, I can't really remember much... I can remember bits and bobs. I remember doing exercises in the physio room trying to build my muscles back up, because the muscles had seized up so just learning to walk bit by bit and learning to push myself in the wheelchair and that."

Jason's experience is similar to those above in that it is an account that depicts dependence both on healthcare professionals as well as his family whom he spent Christmas with.

Despite the participants being able to remember relatively little about events in the immediate aftermath of their brain injuries, there were still some interesting insights that referred to the importance of dependence, independence and interdependence in rehabilitation and their contribution to identity (re)construction to be gained from this portion of the interviews. This is particularly evident when Eric

described how his tablet was dropped onto the floor. When analysing these experiences, I was struck by the powerless state of complete dependency that the participants conveyed.

Post- acute stage of injury

The participants' accounts of this stage were a little more detailed. In analysing this data, once again, the theme of dependence, independence and interdependence seemed to be particularly prominent. One topic which re-occurred during the interviews was the participants' recollection of the members of staff within the hospital/ rehabilitation unit. If identity is made up of many interconnecting facets as my conceptual framework suggests, then it would seem to follow that interactions with healthcare professionals would play an important role in identity (re)formation for the participants. This section explores the way the participants framed these early interactions. Karl talked about a rehabilitation professional he was particularly fond of:

> "I remember one lady in particular. She was just a normal lady, bit like your grandma, lovely lady and there was no judgement there. There was no – she would ask you if you were okay and she just kept an eye on you and she was fine, there was no restrictions there, she was good as gold."

After a little probing into the detail of the reasons why this rehabilitation professional made a positive impression on Karl during his rehabilitation, he commented further:

> "She was just a nice lady, just a generally nice person and I think she gave you the impression that she actually felt sorry for you, which is what you want people to feel, you want people to feel sorry for you. You want at least one person to feel sorry for you that when you do feel crap you can talk to them, you don't want people constantly telling you, "Oh it'll be alright." You want somebody to actually say, "No. This isn't going to be alright. It might become alright, but the chances are you're going to be like this for a pretty long time." So you want somebody to tell you the truth and she tells you the truth, which then you respect her for that don't you?"

In this excerpt Karl refers to the way he attached great value to being told the "truth" about his situation which indicates the way Karl preferred equal and reciprocal relationships at the time where he was treated as a competent adult. When talking about his rehabilitation professionals, Sam notes:

> "I liked most of them really... We did have nicknames for them and they took it on the chin, they understood, and I really had great fun with one of them... my occupational therapist... Maureen, she's really lovely. Yes I do miss her, she was so, always willing to help and consequently help me improve really."

Similarly, Sam is stating how he enjoyed the camaraderie with rehabilitation professionals, where he was conceptualised as an equal, whom with the rehabilitation staff could share a joke. Rob talked in a

similar way about the way that he was dealt with by the professionals involved in his rehabilitation:

> "I was treated very well, I was happy with it. I thought they supported me really well and we had a bit of fun as well."

Despite highlighting that he could remember very little about the early stages of his rehabilitation, Jason recalled a particular member of the nursing staff whom he was fond of:

> "I remember one nurse... Lynne she was called I think. She was a matron I remember that bit... She was a nice person; she helped me out all the time. She used to come and talk to me about my injuries and things like that... She used to say that I have to keep trying and that I'll get better soon."

The way that the participants can remember relatively little about early interactions, but can remember details about individual health care professionals says much about the importance that the participants attached to these interactions in their overall experience of ABI and ultimately how they may have helped shape their identity (re)formation.

Generally speaking Eric was also reasonably pleased with the care he received in the very early stages of when rehabilitation started. Eric too states how he appreciated sharing jokes with some of the staff. Analysing this excerpt according to a 'rhizomatic' and 'nomadic' conceptual framework emphasised the way Eric required help in

certain spheres of life, such as walking and so on, but appreciated the recognition of competence in other areas (such as a recognition that they had a sense of humour). However, he noted a difference in attitude between staff, which he attributes to different professions:

> "I liked most of them [the staff] yes, the physio's were brilliant, they made it, made me laugh... cause with some people in the hospital there was nothing, they didn't seem to care really like you know, I thought anyway."

When compared to Eric's appreciation of staff who engaged with his sense of humour, it is interesting that he makes the deduction that many members of staff "didn't seem to care really" Eric, together with many of the participants appreciate the rehabilitation professionals who engage with them by sharing jokes and so on. The participants therefore, attach value to being treated as equals who are capable of sharing jokes and so on. This concept is reinforced in the following excerpt, where Eric talks about the lack of attention received from some staff within the early stage of his rehabilitation. This was clearly was a source of frustration to Eric. He continues:

> "Well... the last ward I was in, erm, the doctors didn't seem to worry because there was, because I was alright sort of thing... they didn't seem to come round a lot, come round once a day like to assess you and that, unless you got a problem like and then you called the button. Nurses come round a bit but doctors didn't see much of. Sometimes it was, well just neglect really. They used to put your food at the end of the bed, if you can't walk or get up out of bed... How am I supposed to get out and get my food and bring it around on the trolley, on the tray thing like you know when I can't get out of bed?"

In analysing this excerpt I was drawn to the sense of great vulnerability in the early stages of rehabilitation following ABI, which serves to further highlight the importance of early interactions and the dependence of ABI survivors at this stage, as well as highlighting the vulnerability of ABI survivors (at this early stage of rehabilitation). This excerpt also further underlines the way Eric feels that healthcare professionals perceived the 'seriousness' of his impairments. This is an issue at the forefront of the debate surrounding brain injury and rehabilitation and one which supports a view that highlights the heterogeneity of ABI. This quotation also highlights the relevance of the debate concerning hierarchy of impairment (Deal 2003) where it is noted that different impairments appear to stimulate different reactions from people in society, and the perceived 'seriousness' of these impairments dictates how people react to individual people. This is neatly summed up by the way Eric says "the doctors didn't seem to worry because there was, because I was alright sort of thing".

I now turn to an exploration of some of the situations when the participants discussed the importance of their families in their rehabilitative journey. I include this section as such outside support seems to suggest the multifaceted nature of identity and therefore is wholly commensurate with my conceptual framework. Moreover these interactions seem to be important to the participants in terms of their overall experience of ABI rehabilitation. It would seem fair to

suggest that family support also plays an important role in identity (re)formation following ABI. However, unlike the previous sections in this chapter, these experiences were discussed in general terms rather than being attributed to a fixed 'stage' of rehabilitation.

Long-term dependence: The role of the extended family in the lives of the participants

In the accounts of the participants, I feel that it is important to note that rehabilitation was often not considered an activity which is carried out in isolation. Rather it seems to be an activity which is carried out with others. In this section I do not seek to demonstrate a lack of agency on part of the participants. Rather, I wish to demonstrate yet further situations which highlight the interaction between and overlap of the notions of dependence, independence and interdependence in the lives of the participants. The participants talked about the role of their family in particular. This is something that was striking in listening to the experience of Sam. Sam notes:

> "My family coming in made a difference actually. My family used to visit me every day, that was a big thing. ... my family used to come in and they used to play Boggle, and stuff like that, mind games, because of my, I had memory problems we played lots of memory games"

In noting the importance of his family in these interactions, Sam is highlighting the situations where he feels his family played a crucial role in his rehabilitation. For example, Sam states "My family coming

in made a difference actually". Sam was not alone in feeling this way. Similarly, Rob also talked about the part his extended family played in his rehabilitation:

> "Family have always been a big part of my life and they have always been around to support me, so without them I don't think I would be where I was today... when I had my brain tumour I also had a girlfriend. We have since split up, but we are still really good friends her and I, so although we are not together anymore... She was a big part of my rehabilitation... she came to visit me in hospital every other night, she was always there as a calming figure to make me smile, make me happy, just someone there... The rehabilitation staff all knew her... at that stage when you are in the hospital you need family, friends, relationships, however you want to phrase them to support you, to make you feel everything is going to be okay."

In Rob's experience, the importance of extended family connections can be noted. The impact of having "a calming figure to make me smile, make me happy" and the importance of having "someone there" is significant. In terms of the role his girlfriend played in Rob's identity (re)construction after his brain injury, it is clear that Rob's extended family were important to him. This is particularly clear in the way that Rob says "you need family, friends, relationships, however you want to phrase them to support you, to make you feel everything is going to be okay".

Eric also told of his great appreciation of the support of his friends and family in his rehabilitative journey:

> "The biggest help really is my family, sticking by me like you know and, it's a hard time for them as well just as much as what it was for me...they used to come and see me every day.. always, always had a member of family with me, and a few friends and that came in, erm, just bring gifts in, drinks and that you know. They also used to help with some brain activities that just kept your mind going like you know?"

As well as further indicating the ways in which family can benefit a person in the immediate aftermath of an injury such as his, Eric also talked of the importance of having a support network that he can rely on helping him over an extended period of time. The way that Eric notes that "The biggest help really is my family, sticking by me" shows that family is very much a part of Eric's identity (re)construction. Consideration of this further highlights the relevance of dependence upon family networks over an extended period of time.

Wayne says his family played a huge part in his rehabilitation and questions whether it would have been so successful if it were not for the support:

> "...my family are amazing... I'm one hell of a lucky guy. My mum has helped me the most... you know she just does so much for me, I wouldn't know where to start, but without my mum and my family I just don't honestly know where I would be."

Karl also talked about the comfort and determination he was able to draw from his family:

> "Having a positive family was a massive thing. Having positive parents. There was no- They didn't give me a chance to wallow."

In this excerpt Karl demonstrates how he feels the positivity his parents were able to instil made a difference in his motivation to rehabilitate and his ability to (re)construct his identity. As well as referring to the role of his parents in his identity (re)construction, for Karl the emotional support of his wife was and still continues to be a major driving force in his rehabilitation. Karl said of his wife that:

> "[She] was and still is a major part of my rehabilitation. My wife was the one who wouldn't let me stay in bed. I resented her for it but she wouldn't let me, on the days I could have quite happily stayed in bed all day, she wouldn't let me... She made me get out of bed. She made me have that shower, shave, whatever... She made me push, push and push and push, because she knew that it was all about confidence, and if your confidence was high, no matter how you are restricted, you can do certain things. If you say my leg doesn't work anymore, I'm not going to walk again, then that's it. I'm not even going to try. Then your leg won't work again. But if you give it your best shot to try to get your leg moving and it doesn't work, you've given it your best shot. But if you try hard and it does work, then it's worth persevering with... I owe her so much..."

Once again Karl demonstrates how his family were crucial in not simply doing things for him, but also in helping to support him in the

maintenance of his motivation to rehabilitate. Karl highlights how he feels the issue of confidence was hugely important in his own rehabilitation when he says "if your confidence was high, no matter how you are restricted, you can do certain things" and indicates the role of his wife in maintaining his confidence.

The empirical data above shows the importance of the outside support of friends and family during the participants' rehabilitation. The participants found the support of family crucial in many ways. The participants did not simply speak of the importance of having people to do things for them, but rather they noted the importance of extended family networks in completing rehabilitative activities, maximising motivation to engage in rehabilitative activities, increasing confidence and so on. The experiences of the participants indicates that dependence is more than simply having a person to do something for you, and as such these experiences seem to further indicate the complexity of the notions of dependence, independence and interdependence in the lives and the (re)construction of identity of ABI survivors. In the following section, I present the experiences of my participants where they highlighted the importance of being around other ABI survivors and rehabilitation staff.

Interdependence: Peer support

Although it has been noted that many disabled people reject such a label (Watson 2002) and seek to be identified according to other aspects of their lives, solidarity between others with impairment(s) has been cited as an important part of living life as a disabled person (Branfield 1998). When carrying out interviews with the participants, I became aware of the close bonds they had formed with others in similar positions and the role that peer support played in their rehabilitation.

To provide an example, Jason notes the importance of meeting other people, who may be experiencing similar problems and talked of how that helps him greatly with his rehabilitative journey:

> "Well I made a good friend called Matt in the rehabilitation unit... A few years ago he'd had a stroke. I became very friendly with him and his wife and his kids... as I said he had a stroke and had similar problems to me... I felt really comfortable talking about stuff with him, because he was going through the same things as me."

Karl told of the great support he received from someone he had met through the Internet. She had sustained a stroke whilst giving birth two years before Karl had his stroke. Karl talked of some the ways that speaking to someone who had similar experiences had helped him. More generally, Karl spoke of how receiving support from others had given inspiration for his own rehabilitation:

> "... I was on *Different Strokes* website... I started talking to a girl... she had a stroke after she'd given birth to her boy, it would be seven years ago now, so she was much further on than I was, but I knew then that when I started talking to her that she felt the same way that I did at that time. So I knew that there was light at the end of the tunnel, although you can't see it... I knew eventually that something good was going to come out of it... I wasn't going to be left like it forever."

In the rehabilitative journey of Sam, the importance of forming relationships with the rehabilitative health care professionals is also evident. In the experiences of Sam below, the camaraderie between himself, other ABI survivors and rehabilitative professionals was also a key source of support and inspiration through his time in the rehabilitation unit.

> "... All the people in the rehab unit were really lovely. All I can remember is they're all so really friendly in there. We had nicknames for them, oh I can't remember, Juicy Lucy, Bob Flobadob... we had a great laugh... I can't remember the other nicknames now. We did have nicknames for them and they took it on the chin, they understood, all the patients and staff were always willing to help and consequently help me improve really..."

Two participants in particular reinforced the importance of belonging to support groups, as this provided an opportunity for them to meet others in similar situations. The participants noted the importance of spending time with others who have had similar experiences. Rob commented:

> "Well as I say, I have still got the friends that I knew as friends since before my injuries, I still know them and I still meet up with them, but probably the best thing for me is to go to groups where there are people in your situation, but you can get to meet people that have been through exactly the same thing as you and from their experiences learn how they coped with their disability".

Rob talked of how making friends with people who may have similar difficulties is important in the long-term and talked of the inspiration and this could provide for his own unfolding journey of rehabilitation.

> "It is seeing what other people in your situation or other people that have been where you have been, how they have built up their strengths and social ability to come to terms with their illness."

Similarly, belonging to a support group was clearly important to Eric as well.

> "Coming here is the main thing I do socially really... I think it's really important... I normally get here about just after 12. I stay until 4, trying to enjoy myself, interact with other people, learn a bit, and then leave here at 4... I really enjoy spending time here with other people with similar sorts of problems."

Eric also talked about the importance of having people around who have also sustained a brain injury. He highlighted the importance of being around people that could identify with some of the same problems he was experiencing:

> "It's nice that people understand what it's like, because some of the problems you got they got

> as well and they understand and you don't feel like you are the only person that's ever had it."

Eric reported "not having much of a social life" outside of the support group. I tried to tease out some possible explanations for this. The way that Eric describes this experience and the discomfort that it imbues, offers some insight into why Eric feels more comfortable in an environment with other ABI survivors and the role this plays in his identity (re)construction following his ABI.

> "I do get angry a lot about people's attitudes towards brain injuries. I get on the bus. I've got a bus pass. I get on the bus and I sit down and people are whispering. That's what I think. People are talking about me. Well, why has it got a bus pass? They don't know nothing about me. Likewise I don't know about anyone else on the bus. Why don't other people have a bus pass? I don't know. That's not my problem. But I don't know why people- people have got to judge, really."

As well as drawing support from a variety of sources, one participant emphasised how he had benefitted from the presence of another ABI survivor in a different way. Karl told of the inspiration he gained from seeing people in a 'worse' situation than him:

> "It's always nice–no, that's wrong. It's comforting to see somebody who's in a worse situation than you are makes you realise that hang on a minute there's something worth fighting for here, I've seen a lad at that rehabilitation centre that all he can do is communicate by flicking his eyes on a keyboard....And he's still happy and this lad was as fit as you like, but he's going to live in that rehabilitation centre for the rest of his life, but he's happy and there can't be anything

> worse than not being normal inside, but nothing works apart from your eyes and being fed through tubes and stuff like that. There can't be anything worse than that... fair play to the lad, because he's a top lad for doing that."

I find this to be particularly interesting and important to discussions of interdependence in the lives of ABI survivors not least are as this experience demonstrates Karl's discomfort at the juxtaposition that he feels between wanting the best for somebody, whilst at the same time drawing comfort from knowing there are people in 'worse' situations.

Inorganic objects as a source of interdependence

Many of the participants reported that they relied and continue to rely on inorganic objects and environments to maximise their rehabilitation. These instances say much about the participants' ability to modify their every-day activities as ABI survivors. However, as well as talking about how the every-day use of devices such as mobile phones and cameras aided their identity (re)construction, the participants also spoke of instances where cars and other inorganic objects and environments aided and continue to aid their ongoing rehabilitation and identity (re)construction.

During a discussion with Sam, the importance of having aids to enable him to remember certain activities was something that was

clearly very important. Sam pointed out that he often uses certain objects to 'jog' his memory:

> "...I've got my phone which I write notes on every day, I've always got reminders on it. My phone is my lifeline really, just little notes about anything really. Appointments or numbers, or who I need to phone, or things I need to get, or shopping list, or anything I'll put in my phone."

Sam continued, and provided some reasons why he finds this so useful:

> "...I first started to make a note of appointments when my occupational therapist suggested that I do so when I was at inpatient rehabilitation. She used to say "always write things down so I can help my memory" I haven't really stopped writing since then. Now I use my mobile phone to remind me of doctors' appointments and things... my mobile phone is basically full, I've got reminders going off every hour with things that remind me of stuff..."

Sam also discussed the way he uses his camera (on his mobile phone) as a useful tool in (re)constructing memories. As such he describes how technology has had a therapeutic benefit in helping to negate his memory recall difficulties:

> "... I take photos of everything really. It helps my memory. See when I was born I have got 20, 30 photos of me when I was a baby but my daughter had more than that on her first day on this earth, I just took so many photos you know... Well I never had a camera before [my accident] or a camera phone because it was 2003, so I don't think I had a camera phone.

> So yes, it is definitely, but like I have said, photos are memories aren't they, so I do like looking back on photos and thinking 'Ah yes, I remember that' you know. Photos do actually help the brain remember things, they do you know..."

The use of mobile phones to help memory was also something that was important to Jason:

> "...I use my mobile phone all the time. Whenever I make an appointment I use my phone like a diary. About one hour before each appointment, I make sure that the alarm goes off to remind me... It really helps me loads. I don't know what I would do without it..."

These experiences provide an opportunity for a theorisation of the (re)construction of identity which conceptualises the person as more than flesh and bones, but rather situates people into wider social networks which comprise many objects both living and otherwise.

Rob spoke of the importance of his walking aid and the role this has played in the (re)construction of his identity. During a discussion with Rob, we began talking about how he visits his young nephew (aged two). He described how he really looks forward to going to his sister's house once per week to visit his nephew. Rob continued:

> "...I go around to her house on a Monday... It's great fun, I play games with him and read him some books and talk to him... He makes me laugh... He has a name for my crutch. He

> calls it Rob's crutch and when I put it in the corner of the room, he talks to it... he calls it Rob's crutch and keeps bringing it over to me... I suppose it sounds a bit weird, but in a way he's right because I'd be lost without it..."

It is interesting to reflect on the way Rob's nephew seems to view Rob's crutch. This refers to the different ways of conceptualising objects such as walking aids and if an alternative way of conceptualising these objects may have implications for the rehabilitation process. If walking aids such as "Rob's crutch" are thought of as part of a person's identity, rather than a solely as means to aid mobilisation and independence, then perhaps healthcare professionals, researchers and so on may think of Rob's rehabilitation and his ability to walk 'independently' in a different way. An alternative conceptualisation of walking aids may frame them as productive and important objects in identity (re)construction, rather than viewing as objects which signify an inability to achieve independence (from objects) or a means by which to achieve independence from other people (Gibson 2006).

Jason stressed the importance of his car in his rehabilitation. He stressed the importance of it in terms of being able to visit the local gym and keep in contact with friends and family.

> "... It's really good having a car... It's a Peugeot 106 diesel. It takes me everywhere I

> want to go. I go to the gym in it. I visit my friends in it and ferry the kids around... I don't how I'd manage without it..."

Sam also noted the importance of having a car and being able to drive particularly in terms of how his car has allowed him to perform everyday family tasks as well as how it has facilitated his rehabilitation:

> "I'm quite dependent on it really, very dependent on it. So it's, I mean it's great to get the shopping or food or whatever. So yes I love it, it's really good...we sometimes, well our daughter's school is just round the corner, so most of the time we tend to walk because it's only up a lane... sometimes when it's bad weather we do try to drop her to school, and when we go shopping like I said, or if we want to visit family or anything like that, family or friends, or take our daughter somewhere nice... It really helps with doing day-to-day stuff."

Similarly to Rob's experience discussing the importance of his "crutch", in the above experiences Sam and Jason talk about their cars as being important constituents of their lives. If their experiences are framed in a different way, a way which suggests that inorganic objects such as their cars become part of the identity reconstruction process after ABI, then this would have serious implications for the rehabilitation process. For example, discussion of the constitution of identity would have to adapt accordingly to incorporate discussions of the importance of inorganic objects and the opportunities they may provide. The data which comprises the above section also

demonstrates the way that my participants are able to integrate impairment into their every-day lives. This highlights the way that the participants feel that their impairments do impact on certain aspects of their lives. However, in the (re)construction of their identity the participants were able to adapt their identities to incorporate impairment based factors. Thus, this would seem to reinforce an understanding of the (re)construction of identity following ABI, which leaves open the capacity to adapt and change in a unique and flexible way.

After drawing on some experiences which demonstrate where my participants used the support of inorganic objects in their rehabilitation, I now continue discussing the notions of dependence, independence and interdependence by highlighting some instances whereby my participants were/want to be a source of support for others. Such a discussion further explores the interrelationship between dependence, independence and interdependence in the lives of the participants by indicating that help and support was seen by the participants as reciprocal rather than these occurrences always benefiting the ABI survivor.

Brain Injury Survivors as Sources of Support

So far in this chapter I have discussed the way that other people, objects and environments have played a part in the rehabilitation and

identity (re)construction of the participants. This serves to highlight the dependence of my participants. However, after analysing the contents of my discussions with participants, it became clear that the participants were keen to discuss situations where they were involved in reciprocal relationships. To put it another way, the participants were eager to provide examples of where their existence could be beneficial to others. This was particularly visible during an interview with Eric when we were discussing the impact of his impairments:

> "It hasn't been all bad...For example, I am more caring now, I am a lot more caring, more about other people than myself...[before the brain injury] I just worried about myself really, you just live life and party and work and that was it like, only had time for myself... now though if I see somebody in need I try to help them out. It's not always the case of financial need but advice or support or just to say hello to someone to make their day like, just anything, fundraising and that you know, things like that really mean a lot to me."

Interestingly Eric views the act of sustaining an ABI as providing him with an opportunity to help and guide others who may be in a similar position.

This is also noticeable in engaging with the experience of Wayne. Wayne discussed some of the ways that he feels he can be of help to others during his time at the support group:

> "I am always cheerful and that. I always want to help people in this place. You know that's one of my things that I like to do in here is help people... I know how it is coming in here,

> being on your own, not knowing what to do, not knowing how to speak to people and I believe that if you get someone that wants to help you, knows what you are going through, that will give you the confidence... because coming to a place like this, this is huge you know and seeing all different brain injuries. You don't know what to do, you freak out a bit, well I certainly did, and now I want to help people so they don't."

Jason too felt very strongly that he gets a great deal of comfort out of helping others within the centre. Jason says:

> "I really like to help people in here [the support group]; it makes me happy... helping people in here makes me happy because I feel I am putting something back into the country, instead of always taking out... yep it makes me feel happy inside myself."

Sam talked in general terms about how his life has changed since his brain injury, and the joy he gains from responsibility:

> "I've changed a lot. I've changed an awful lot since my brain injury... I spoke to my friend yesterday, and he said you have changed a lot, but in a good way, and that's it really... before [the brain injury] I was quite reckless but now I am so much more quiet; I am a family man. I am getting married later this year, and I have two kids... It's quite scary to think that I've got all this responsibility. I really like it though, it really makes me feel good."

Sam's experience of "chang(ing) an awful lot" since his ABI provides a neat example of the way Sam believes he has (re)construced his identity to integrate his impairment. When analysing this excerpt, I regarded it to be important to recognise that it is now approximately

10 years since Sam's ABI. The period of time that has passed since his ABI may be important to his ability to reflect on the change to his life.

Karl spoke of how it took quite a long period of time for people to feel comfortable to ask him to help them with certain activities and the frustration this invoked:

> "Something that really frustrated me was when people felt they couldn't ask me to do stuff. For example, my dad will always ask me now but he didn't ask me for a long, long time...we both like doing things: building stuff and making stuff and he wouldn't ask me... I've always offered and he still didn't ask me. But recently he started asking me for help. So obviously he's worked out that he feels that his confidence has come back for me to be able to do that. It doesn't kill me to be able to do what I was doing... I wish people would just ask."

In a later interview Karl explained why he desperately wanted to be in a position to aid the activities of others:

> "...whenever I can I want to help people. I just want to help just the same as when I was helped just after the brain injury... I just really like helping people."

Karl's emphasises the importance he attaches to reciprocity as he feels that he is keen to repay the help and support he received and continues to receive throughout his rehabilitation journey.

Rob discussed how his injury has given him fresh insight into how to judge a person. This is demonstrated in the following exchange:

> Rob: I didn't have such a strong feeling to help other people before my injuries. I would always judge someone by looking at them, whereas now I think you have to get the time to know that person.
>
> *Me: And do you see that as a good thing, a positive change?*
>
> Rob: Definitely, definitely a good change because as the famous saying goes, you can't judge a book by its cover."

In highlighting the way that he believes "you can't judge a book by its cover" I felt that Rob was encouraging people to engage with the complexity and the multifaceted nature of his identity, rather than basing their impressions on a single facet of his identity (his impairment). In terms of care and support, Rob is promoting an appreciation of concepts such as dependence and independence which are simply viewed in polar opposition, but rather viewed as capable of overlapping in unexpected ways.

Interestingly, Eric also warned against the dangers of basing impressions of a person's identity on a single factor when he talked of how he liked to help others in terms of his every-day interactions with members of the public:

> "You've always got to treat people with respect and kindness, never judge a book by its cover, you've always got to look after people...It don't hurt to smile at someone

> down the street, just to say hello sometimes you know... I am a lot better since my brain injury... Sometimes I get angry going up the high street because people get in my way, but most people are quite friendly and they are okay like you know. For example, before I was ill I used to open the door and just forget about who is behind me and shut the door on them like you know, but now I'm there for hours like, letting everyone in."

The way that Eric states "I am a lot better since my brain injury" demonstrates his belief that his ABI has had a profound effect on his identity in this area of his life. This further encourages a conceptualisation of ABI as an opportunity for growth, rather than providing a set of impairments that need to be fixed.

In terms of providing support and receiving support in a reciprocal way, Sam too talked of his propensity to help others. Sam indicates that this is a clear change from his pre-injury self; it is something that has grown since his brain injury in an unexpected way. Sam commented:

> "I love helping people when I can. The thing is it's usually me asking for help! Since my brain injury I have learnt to ask for help if I need help. Before I used to struggle on all the time, but now I don't struggle with things, I would say don't be afraid to stand up and say I don't understand this or that... I still do that now in my group. There are two university teachers in my group, and one said something last week, and I said, Hang on a minute, what does that word mean? There are other times when I can help people. That's why I like working in the CAB [Citizen's Advice Bureaux]. Do to others

> as you would have them do to you. That's my motto."

In using the phrase "do to others as you would have them do to you" Sam indicates the mutually dependent, reciprocal relationships that are in place in his life.

Wayne talked of how he feels he can be of help with regard to employment situations. Wayne talked in great detail about the way he enjoyed his voluntary work with charities. Importantly, he stated that he had far less propensity to engage in helping others before his brain injury. During a conversation regarding some voluntary work that he did at the local arts centre for people with learning difficulties, Wayne commented:

> "A few years after the brain injury I thought to myself right I am going to do voluntary work. I want to do voluntary work that I enjoy doing... I enjoyed working at the exhibition centre and helping them...the look on their face when they have done painting you know, they were so proud of themselves, so happy, big smiles and it's just priceless to see that big smile on their face and be so happy with the art work that they have done. You know that you were helping them and you just can't beat that. Well nothing can beat that, you know that feeling that you get and to see that delight on their face."

In the above excerpt, it is relevant to highlight the way that Wayne is encouraging recognition of the way that notions of dependence,

independence and interdependence vary within different parts of his life. When engaging with the experiences of Wayne, it is clear that in some areas he is dependent upon others and during some activities others may be dependent on him. This serves to further problematise the train of thought which states that the act of providing support and receiving support are polar opposites. It is noteworthy that the acts of providing support and receiving support change during his identity (re)construction following his ABI, but at the same time both are important to Wayne in terms of his identity.

For some participants the issue of providing care and support to others was a notion that had importance when they imagined their future identities. For example, Rob talked about how he envisaged his future self and the role he feels he could play within society:

> "I think I would like to be a spokesperson for certain disabilities and illnesses... I think people need the help with it. And it all comes back to learning to live with your illness or disability and once you've come to terms with it, you're more able to cope with it and deal with the issues. I want to give something back to the country that saved my life."

Since his brain injury, Karl reported becoming far more interested in pursuing opportunities for voluntary work and helping people such as those who may be homeless through engaging in some sort of charity work in the future. The act of providing support to others was very

important to the participants. I conclude this chapter referring to the notions of dependence, independence and interdependence in the (re)construction of the identities of the participants by highlighting the experience of Karl:

> "When people perhaps ask you to do things, perhaps they think twice about asking you to do stuff, asking you for help. I would help anybody. If I can do it, I'd help somebody do it, but perhaps they'd think twice about asking. Perhaps they'd think, well, is it going to knacker him out or is he going to be able to do it now? Can he climb that ladder? Can he hold that? Can he cut that? Whatever... I love helping people, and just wish they would understand that it doesn't kill me to be able to do what I was doing."

This excerpt highlights the importance Karl attributes to being adjudged by others to be capable of providing support. From this, it is clear that being judged as having the capability to help others is an important component of the (re)formation of Karl's identity.

I will now briefly revisit some literature which pertains to the notions of dependence, independence and interdependence in disabled people's lives. I will follow this with the discussion of where my data can be situated within this literature.

Situating this chapter within literature which seeks to explore the relevance of dependence, independence and interdependence in disabled people's lives

Perhaps due to the rapid rise in the use of technology in every-day life, debates surrounding the issues of dependence, independence and interdependence seem to be particularly relevant when exploring the construction of identity among dis/abled people. Much literature which explores the relevance of these notions in disabled people's lives cite the significance of the contemporary social landscape (Gibson 2006, 2012; Kafer 2009; Reeve 2012; Shildrick 2002) in shaping the way that disabled people's experiences and identities are constructed. For example, there is much discussion surrounding whether technology is used as a tool to 'fix broken bodies' (Kafer 2009: 224) or the extent to which the way people use technology can contribute to 'unsettling dominant discourses of disability' (Reeve 2012: 103). Somewhat surprisingly, in these discussions there appears to be lack of literature which explores the way the acts of not just receiving support, but *providing* and being sources of support impact upon the identities of disabled people. Therefore, I have highlighted the situations whereby providing support was pivotal in the (re)construction of the participants' identities.

In this chapter I have sought to encourage recognition of the views of disabled people concerning issues of dependence, independence and

interdependence with reference to ABI survivors. I propose that the data in this chapter suggests that there is a close and changeable relationship between dependence and independence in the lives of the *participants*. The participants have a complex relationship with the notions of dependence, independence and interdependence where the acts of providing or receiving care are seen not simply as 'a means to achieve independence'(Gibson 2006: 187) but rather as key constituents in the (re)construction of their identities.

Conclusion

In this chapter I have analysed the experiences of my participants according to a rhizomatic and nomadic framework and explored whether for them, their rehabilitation was a sole venture, or one which is negotiated in collaboration with other people, places and objects. At the beginning of the chapter, the notion of receiving care and support was most important. However, as their rehabilitative journey continued, my participants seemed to need and desire the support of others less and less. Towards the end of the chapter I detailed some of the ways in which the participants claimed they have been able to provide support to others. The interchangeable nature and relevance of dependence, independence and interdependence in the lives of the participants indicates that assertions which indicate that rehabilitation a quest to (re)gain independence (Barnes 2003) may not be relevant. The experiences of the participants seem to indicate a closer relationship between both dependence and independence. This

chapter is directed towards stimulating discussion which adds to the body of evidence which seeks to determine whether rehabilitation after ABI is conceptualised as a time which is defined by the ability (or not) to achieve independence. I found the discussions regarding my participants eagerness to help others to be particularly interesting, especially as this was in opposition to many trains of thought regarding the lives of ABI survivors which see them purely as victims or people who should be pitied (Lorenz 2010; Sherry 2006). Overall, my analysis of the data in this chapter suggests that there were specific times where each of the notions of dependence, independence and interdependence were relevant in the rehabilitation and ultimately the identity (re)construction of the participants. I continue the exploration of the identity (re)construction of the participants in the following chapter which investigates the notion of time with particular reference to the participants' unfolding futures.

Chapter 6 Exploring time in ABI rehabilitation: towards a rehabilitation imagination?

Introduction

In this chapter I reflect on the experiences of the participants as they are related to time in their rehabilitation with particular reference to the unpredictable nature of the future in their identity (re)construction. I seek to highlight some instances where my participants are continuing rehabilitative activities and therefore continue to (re)construct their identities long after their discharge from rehabilitation services. In short, the data in this chapter explored the lives of the participants on a long-term basis which explores the way that they (re)construct their identities. In terms of my research questions, this chapter clearly addresses the question which seeks to determine when, where and how rehabilitation takes place. I begin by highlighting some of the experiences of the participants which relate to instances in very early rehabilitation where they talk of their perception of the way medical professionals seem to view rehabilitation.

As this chapter unfolds, I draw attention to the extent to which the experiences of the participants demonstrate that the future has been considered in their rehabilitation. Thus, this chapter takes its name

from C. Wright Mills' seminal text *'The Sociological Imagination'* (1959/2000). In this text, Mills demonstrates how personal life events can be utilised to echo wider social inequities. This chapter seeks to capitalise on the transformative power of the imagination to enable an interrogation of the way time is conceptualised in the (re)construction of the participants identities. This chapter uses the understanding of the word 'imagination' to investigate the role of time in the (re)construction of the participants' identities. The word 'imagination' is also used to consider what the rehabilitated body may look like. Analysis of the accounts of the participants, suggests that their bodies; their identities have been adapted to incorporate their ABI. As with the previous chapter I present the early parts of the rehabilitative journeys of my participants first. Before exploring the experiences of the participants, I discuss some of the ways a rhizomatic and nomadic conceptualisation can enhance understanding of the role future imaginings play in identity (re)construction following ABI.

What can a rhizomatic and nomadic framework and the discussions regarding the 'rehabilitation imagination' after ABI?

Analysing my data according to a rhizomatic and nomadic framework has enabled me to explore how the participants have (re)constructed their identities over a long period of time. Rather than conceptualising impairment as a stable phenomenon characterised by static notions of loss, a rhizomatic and nomadic framework would seek to:

> 'engage in affirmative politics, which entails the creation of sustainable alternatives geared to the construction of social horizons of hope' (Braidotti 2011b: 267)

Rather than 'engag(ing) in affirmative politics', the way that the participants recall many experiences suggest that their impairments are being conceptualised as something that are fixed and inflexible. The propensity for growth and the (re)construction of identity to incorporate any impairment-based considerations is not realised. In addition many medical professionals do not situate impairment in collaboration with other facets of identity such as those involving family, friends, employment and so on. In short these recollections suggest that impairment is often conceptualised in an ever-steady way and something that cannot change due to the passing of time.

Previously, engaging with these every-day experiences of disabled people such as ABI survivors has resulted in a largely 'melancholic' discussion of barriers to participation (Campbell and Oliver 1996) or depictions which portray the identity of a person to be 'damaged' (Nochi 1998) by the medical dimensions of impairment(s). Framing these experiences in a 'rhizomatic' and 'nomadic' way can enable a less melancholic realisation without turning to a reliance on the brute 'realities' of impairment (Roets and Braidotti 2012). With regard to the every-day experiences of the participants in this study, a nomadic conceptualisation has been said to:

> '... look for the ways in which otherness prompts, mobilises, and allows for flows of affirmation of values and forces that are not yet sustained by the current conditions' (Braidotti 2011b: 305)

When thought of according to this framework, the every-day experiences of the participants can be thought of in a way which seeks to celebrate their achievements and highlight the achievements of the participants rather than solely bemoaning the factors which limit them.

For example, the way the participants have adapted their actions to integrate their impairment(s) is interesting when a nomadic framework is employed. Framing the every-day experiences of the participants in this way can provide a neat example of where the participants are aware of the limitations of their physical impairment(s) as well as societal barriers and have adapted their identities accordingly. This enables recognition of the capacity of ABI survivors to demonstrate a degree of agency rather than relying on negative theorisations which depict ABI survivors in terms of what they may have 'lost'.

Furthermore, it may be worth considering how the acquisition of these impairments may have provided participants with skills in another area such as increasing their perspective on the importance of various activities. This may enable a consideration of whether brain injured people should be encouraged to take part in activities that are new to

them and they may be able to perform to a standard that is reasonable to them.

Overall however, thinking of impairment(s) in such ways can enable a productive discussion of the possibilities of impairment, rather than a wholly negative conceptualisation. Thinking of the identities of ABI survivors according to a 'rhizomatic' and 'nomadic' framework, enables the commentator to regard their identities as being dynamic and never still (Braidotti 2011b) rather than passive entities defined by the steadiness and the restriction of their impairments.

The possibility for future growth is a notion that is evident when engaging with Sam's experience of his ABI rehabilitation. Sam's experience signifies that the acquisition of new skills is possible for an ABI survivor. Sam talks of his new-found interest in writing. This is an activity that Sam has become interested in only since his ABI. The acquisition of new skills and engaging in new activities is relevant when exploring a rhizomatic and nomadic conceptualisation of rehabilitation. A rhizomatic and nomadic conceptualisation of rehabilitation remains open to the acquisition of new skills rather than conceptualising the impairment as a wholly fixed and:

> 'individualised phenomenon (which) implies negativites, including pathology, pathos, social death...' (Roets and Braidotti 212: 161)

Therefore the unpredictable nature of future lives seems to align with a rhizomatic and nomadic vision of ABI rehabilitation which take account of future life events. Moreover a rhizomatic and nomadic vision of ABI rehabilitation leave space for these unknowable, future life events to be situated in the (re)construction of identity following ABI.

The following quote seems to capture the transformative potential of a rhizomatic and nomadic, future-orientated approach to rehabilitation when it is suggested that according to a framework based on the thoughts of Deleuze (and I would suggest Braidotti) that:

> '... it is hard to see what differences between the existent and the non-existent, if the non-existent is a possibility that retains all the characteristics of the existent'. (Grosz 1999: 26)

When considered in terms of ABI rehabilitation and in rejecting the idea of impairment as a fixed, 'individualised phenomenon' a rhizomatic and nomadic rehabilitation would not treat impairment as necessarily leading to 'social death'. Rather, factoring impairment with the myriad of other social factors that determine the (re)construction of identity following ABI leaves space for uncertain and unpredictable growth through the acquisition of new skills.

"He killed me right then and there": Professional imaginings

In this section I seek to present some examples of the rehabilitation of the participants which enables a critical examination of the way the participants felt professionals imagined the future. Karl recalled the moment when he was told about what had happened to him in detail and talked of the way his propensity for future recovery was discussed. The way that Karl recalls the way his medical professional imagined his future is interesting in the way that the medical profession spoke in terms of permanent loss. Karl recalled that he was told:

> "[The] Doctor said to me 30 years old I was, he walked into that room and he said to me "You've had a stroke." This is on my own as well, nobody else there. "You've had a stroke." Then his parting shot was: "The chances are this is how you will be for the rest of your life. You will probably never work again. Your chances are you're never ever going to drive again."

This is in direct contrast to a 'rhizomatic' and 'nomadic' conceptualisation of rehabilitation, when probed for a little more detail regarding the conversation, Karl continued:

> "That was it and that's how he left it, so just completely destroyed me in the space of five minutes... He killed me right then and there... Just telling you that you've had a stroke is enough I think – and then later on down the line even if your GP said it at least you actually know your GP... *when somebody tells you you're not going to be able to do something then at that time who are you to argue?*"

In this excerpt Karl talks about how this interaction had a significant impact on his identity (re)construction after his ABI. In particular, when Karl says "*when somebody tells you you're not going to be able to do something then at that time who are you to argue?*" is important, not least as it serves as a reminder of the imbalance of power in medical situations. It is clear from this excerpt that Karl believes these early interactions, especially when they involve a person who is in power and whose opinion you respect, have a long-lasting effect upon the person's identity (re)construction after ABI.

During a conversation with Wayne the initial discomfort that is experienced by someone who has sustained a brain injury was reinforced. Wayne highlighted the level of pain and confusion that was constantly present during the immediate aftermath of his brain injury.

> "Well, you know, you're just absolutely distraught because you feel ill, your head's hurting... My head was hurting. It was horrendous. Because of obviously the brain injury and the surgery. I went under surgery at least about three times. My head was hurting. I couldn't sleep. I was in pain in the stomach because of where they put the tube in. It was horrendous. It really was."

Wayne discussed his feelings when he had been told that he would never understand things very well and would forever struggle with his written and verbal communication skills:

> "I just felt stupid. You know? That's the only way to sum it up. You feel like a kid. You feel stupid. You feel as though no one understands you. You know? No one gets how you feel. I'm not going to lie to you... My whole world had just fallen apart."

This quote is similar to Karl's experience above in that it can provoke wider discussion as to the way that professionals imagine the future. It would seem to follow that the way you classify yourself will have a major effect upon the (re)construction of your identity. The way that Wayne sums up his feelings by saying "I just felt stupid" would have a lasting effect upon the (re)construction of his identity. This is important considering my analytical framework which seeks to analyse the (re)construction of the identities of the participants using a framework which highlights the 'rhizomatic' and 'nomadic' features of identity (re)construction after ABI. The use of these concepts underlines the importance of the uncertain passing of time and does not seek to reinforce the linearity of time. The future is not seen as far away and unreachable, rather under this framework the notion of the future is very much entangled with the past and present in an acknowledgement of the construction of identity, whilst enabling an interrogation of the extent to which rehabilitation is an affirmative intervention. The absence of such an understanding can be observed in both Karl and Wayne's feelings that "he killed me right then and there" and how "my whole world had just fallen apart". Neither participant was informed of the possibility for future growth. It is clear

that a framework which promoted the rhizomatic and nomadic nature of identity was not employed on these occasions.

Similarly, Rob talked of how the permanency of his impairment was reinforced to him and how this directed his thoughts about the future. It is interesting to note how Rob has come to see his impairment as his responsibility and something he "has to deal with."

> "Well I got the diagnosis that my left hand will never be as strong as it was before my brain tumour...it will never recover to the stage it was before my injuries and illnesses, and that is just something I am going to have to deal with in my own head."

These early experiences and their implications relate to my analytical framework in the way that the various impairment(s) that the participants refer to are conceptualised in a static manner with little regard for the future. In terms of the (re)construction of identity of the participants, it is interesting that they recall these early interactions with professionals in considerable detail. This may well indicate the way that these early interactions with professionals have a long-lasting effect upon a person who has sustained ABI. I now present some more participant experiences as they relate to social interaction.

The notion of time in social interaction

In this section of the chapter, I seek to draw on my empirical data to investigate the way that the participants engage with their social and

familial networks in indeterminable and unexpected ways. I present the experiences of the participants as they relate to the uncertainty of the future. This relates to my analytical approach in the way that these experiences indicate the unpredictable nature of the future. For example, the opening excerpt in this section addresses the way that Sam has acquired new skills following his ABI. It is important that in the experiences of my participants the acquisition of new skills is not something that was addressed or 'imagined' by rehabilitation professionals. This information serves to highlight the importance of forming social relationships that were impossible to predict. In this way this data adds to discussions surrounding the way the future is 'imagined' in rehabilitation following ABI. It serves to explore the (re)construction of identity following brain injury by exploring the way that experiences following ABI have been integrated into the (re)construction of the participants identities. An example of the acquisition of new skills following ABI is provided by Sam who talked of his (recently acquired) interest in writing and performing.

> "I belong to a writing group which I go to once a fortnight... I go down to see other writers, and we meet up and read each other's bits what we've been writing, and I hope I can get something published this year... There is also an open mike night that I have just started going to. I've only been to one so far, but someone from my group told me about it actually, and I stand up and I read my poems out to strangers, like 30 odd people, which was pretty scary at first. It took me a while to warm up, but it's the first time I've ever read out anything to anyone, to strangers. I've always read, I've always been confident reading in front of friends and family, but it's a different

> ball game in front of strangers. But I'll tell you what I felt good after, once I left I felt, I was really happy, I was buzzing, so I'm hoping to do that again soon, definitely, definitely.

During discussions with participants, the importance of family and friends was impressed upon me. These interactions occurred after formal rehabilitation. The significance of these interactions are not knowable during the 'normal' course of rehabilitation and therefore do not inform rehabilitation practices. However, Rob was keen to talk about these experiences and explained how he likes to visit friends and family in the local area:

> "I see friends. I go out and see my friends quite a lot in my spare time...Maybe I might go across to a nearby town because I used to live there, and like to go across and see all my friends there. Maybe we might go out for lunch or maybe we might go on a road trip. I will go up and see my Nan and Grandad, play cards with my Grandad, have dinner there with my Nan and Grandad. I like to do that."

Jason talked of how his brain injury has affected his relationship with his wife. He finds an appropriate and productive way of releasing his anger that he attributes to his brain injury:

> "Ever since the brain injury, there are some days I get mood swings...Like it depends what day I'm having, I'm either grumpy or happy and things like that... When I'm feeling grumpy, I tend to go to the gym or go on the beer... I like the gym, I go about four times a week... It lets my aggression go."

This experience aligns with previous participant thoughts as it is impossible to know whether any of these activities could have been foreseen or 'imagined' during Jason's formal rehabilitation.

Karl talked of the great help and support that he has received from his wife. This extract directly relates to the way that Karl attaches great importance to the notion of time and particularly the way that his wife knows the nuances of his identity and "can understand what goes on in your head a bit more" as she has known him such a long time. In the discussion Karl highlights the importance of his wife in his identity (re)construction.

> "She understands what goes on in your head a bit more than what people from the outside can see... She's my best friend and I'm her best friend, and that's how it's always been, so we just tend to do everything together [apart] from on a Wednesday when I come to the support group.,, Well, I've been with her since I was 20- No. It was older than that. 17. And then we've been living together since we were 21, and we're 33 now."

Fluid lives

In order to contextualise the experiences of the participants, it is necessary to engage with the details of their unique lives. Due in part to factors such as age (all participants are aged 25-33) and the amount of time since their brain injury (3-13 years) their daily lives have changed a great deal since their brain injury. It is therefore impossible to demonstrate through empirical data whether some of these changes

especially regarding social interaction can be attributed to their brain injury itself. It is notable however, that the participants use their experience of ABI as a reference point for contrasting present and future activities with past activities. An example of this is demonstrated in an excerpt from conversation with Eric. Eric talked of the way he thinks he may have changed simply due to his age:

> "I guess I was quite selfish when I was younger. I just worried about myself really at that time, you just live life and party and work and that was it like, only had time for yourself. Yes you had time for your friends but I suppose I was just a normal 19 year old, just enjoying life.... I don't know if I want to go back pubbing and clubbing and that you know, I want something less you know, I want to be socialising but I don't want to go clubbing and that. I am, I class myself too old for that now like you know."

Eric also noted the way the passing of time has influenced the type of holidays he now likes to take.

> "My ideal holiday is to go back to Brixham in Devon. It's nice down there, it is. I like quiet holidays now...It's a quiet place; the people are friendly down there. There's no hustle; there's no bustle. People don't get in your way. People are pleasant. People are nice. People appreciate you. You can go in a shop and people will say, hello, nice to meet you. And where are you from? Oh, I'm from Exeter. Oh that's nice. You know? And they ask you about Exeter and you ask them a bit about Brixham and that, and it's a lovely place. It's a lovely place."

The way that Eric values the way that he feels there is "no hustle (and) bustle" and the way that "people are pleasant" collaborates with his

previous assertion regarding the way that he feels he is "too old" to enjoy nightclubs. This adds to the knowledge concerning the (re)construction of identity following ABI not least by highlighting that there are a number of factors to consider in addition to impairment(s). Karl also talked of the importance of normative life events such as having children and the way that his life has changed since that event:

> "We always have tea around half-four-ish, and then play with the kids for an hour and then the little girl goes up to bed at 6 to go to sleep at 7, and then the little boy goes to sleep at 7. And then it's whatever then. Probably normally just watching telly, just relaxing. Busy day with two children."

Similarly, Sam talked of how his life has changed. Crucially he talked of how it has changed since he had children.

> "Life, it's changed a lot actually, it has changed a lot, because I used to be.., I still really like music, but I used to sit here listening to Radio One, and this is back in the day when I was younger. But now I'm a family man and we do enjoy watching some shows on television, like CSI and Merlin, and CIS. So we, once my daughter goes to bed at 7 o clock we read her a story every night, one or two stories every night, we take it in turns on that as well, one night it's my fiancée's, one night it's my night."

This excerpt also highlights that the passing of time indicates that life changes. The way that Sam's life has changed due to the passing of time, the act of becoming a father was a key reference point in the addition to his ABI. For Sam, there are more factors to consider in the

(re)construction of his identity than simply an analysis of the impact of his impairment(s).

In opposition to the above statements Sam discusses the way that he has changed partly due to time. However, crucially in this excerpt Sam appears to attribute the change in his identity in relation to his accident rather than indicating it is solely due to the passing of time.

> "Before the accident I was quite hectic really. I've calmed down a lot, I take it so much slower now, which I prefer really, I don't like the fast life anymore. It scares me really. Also things that I've changed, I don't like too many people, crowds, I was never fond of crowds, but now I can't stand crowds... Yes I was one of the lads really, all about my mates not the, I'd see a few girls but not really serious. But now I'm a family man and that's it really, I'm not really like that anymore...sometimes though I get a bit sad and wish I could just go back to the way I used to be. Not the way that I used to be, just the way I used to think, the way I used to process information and all that, because it's all changed. Yes it does get a bit hard sometimes."

My analysis of this excerpt suggests that although other activities, particularly unforeseeable activities (such as having children) do have an effect on the (re)construction of the identities of the participants, sustaining ABI does indeed have a profound effect upon the (re)construction of the identities of the participants. This suggests that both impairment-based, and socially-based factors are important as they relate to the future in the (re)construction of the identities of ABI survivors.

Sustaining ABI has provided a reference point for the participants in thinking about the (re)construction of their identity after ABI. The participants talk about the experiences with direct reference to "living the normal life". Sam in particular talked in detail about how his life has changed. Once again, it is impossible to determine to what extent this is due to his ABI and to what extent this change may be due to the passing of time. Towards the end of the excerpt, Sam seems to be rejecting the notion of normalcy, of living 'the normal' life. His views seem to align far more with a never-steady, rhizomatic, nomadic and unpredictable vision of life.

> "Life now is completely different. It was completely different. I'll have to try and think how to explain it really. It's everything about me has changed, everything. The way I talk, the way I think, the way I process information. The way I look, it's just everything; even the way I dress has changed to be honest. *But that's part of growing up as well I think*, I don't think it's bad, it's different isn't it?"

In contrast to Karl's opinion regarding the importance of normative life events such as having children, Karl also talked of how straying away from normative ways of being was also acceptable to him. Karl seems to be comfortable with living a 'different' life.

> "I class myself as living a retired life at the age of 33. People say, oh, I wouldn't want to do that sort of thing but until they've actually tried it for a few months, they'd soon turn around and say, well, I don't really want to go back to work...but as soon as both kids are at school I want to get an allotment and do some voluntary work. I'll need to fill my day."

The experiences in this section so far, directly relate to my discussion of the (re)construction of the identities of the participants and how they appear to be flexible due to factors such as the passing of time rather than being fixed and static. The use of my analytical framework which highlights the 'rhizomatic' and 'nomadic' features of identity has enabled me to discuss the impact that the passing of time and changing interests has on identity (re)construction following ABI. For example, the use of this framework enables a view of Karl's identity which does not highlight the way he is "living a retired life at the age of 33" as something that is necessarily problematic. Rather a 'rhizomatic' and 'nomadic' framework enables a view of this which takes into account the wider situation of Karl, whilst not restricting opportunity for future growth and change.

One area where the perspectives of my participants were fairly similar concerning the length of rehabilitation was when discussing how their identity had incorporated their ABI. Most participants stressed that this was a gradual process which had taken years to occur. This adds to discussions of how rehabilitation can be 'imagined' for ABI survivors as their data in this section indicates the importance of the passing of time in the (re)formation of the identities of the participants. It is particularly relevant to my analysis that the participants seem to integrate their impairment(s) into their identities rather than simply focusing on the restrictions that these impairment(s) may provide. This instances draw attention to the fluid

and uncertain passing of time. Some examples of these 'epiphanic becomings' are presented below.

An example of the importance of gradual acceptance is provided when turning to the experience of Rob. Rather than having a single definite event which starkly changed Rob's perspective on life it appears that he has integrated his impairment into his life in a gradual way, over time. Of his rehabilitation Rob noted:

> "Well, over the years I've sort of learned what I can and can't do. And over the years, since my brain injury, the cause of my left-side disability, I've come to terms with it. I know people look at me and stare at me because I may walk funny, but in my own head, that's who I am now."

Similarly for Sam, his rehabilitation has been a gradual process which is still in progress. This was demonstrated when discussing employment. Sam works voluntarily in the Citizen's Advice Bureau. He hopes that this may lead to a permanent job opportunity. When asked to describe his feelings related to his job, Sam commented:

> "I come home sometimes and I feel actually my life is not that bad really, because I work in citizen's advice the people that phone up have such big problems, you know, I know I have had a brain injury but I have learned to not, I was only saying this yesterday actually, I have learned since my brain injury, originally I was picking out all my flaws, I had so many problems, but I have learned just to deal with them now and ignore them almost and just focus on the good things in life really, so yes

> citizens advice is really good for me, I really enjoy that."

A key constituent in the rhizomatic and nomadic analytical framework I have employed is the relevance of thinking about impairment(s) in affirmative and 'non-melancholic' ways. The way that Sam says he likes to "focus on the good things in life" provides a neat example of the way that discussions surrounding the (re)construction of his identity following his ABI does not necessarily need to focus on issues of impairment and 'loss'. Instead, Sam's identity (re)construction is a gradual process which involves many different factors including a comparison with the lives of others around him.

Making sense of rehabilitation through participant experiences: "I think it should be a long term thing really... until you don't need it anymore"

The participants spoke of the length of rehabilitation as it related to their unique rehabilitative journey. As such, it would appear to be important to note the significance that they attribute to this in making sense of their experiences. Eric gave his opinion on the length of rehabilitation, during a conversation which was directed at explaining his own rehabilitation experiences.

> "I think it's a long term thing really, you know, I don't know how long you would get it for like but it should be until you are better anyway like, until you don't need them any more yes... Well to me [rehabilitation should]

> support you in things what you are doing, help you erm, say work, keeping in work and that you know, keep... you know the support, keeping that job or something or support you in activities that you do or just to go along and take a bit of pressure off you... I think rehabilitation should go on until you don't need it no more."

A framework which attributes a degree of uncertainty and unpredictability to the lives of the participants and remains open to long-term change is needed to make sense of this excerpt. I suggest that a rhizomatic and nomadic framework would account for the subjective and varying nature of rehabilitation which is unbounded by time and place. Concerning the length of his rehabilitation, Rob spoke of his early attempts at entering education environments:

> "A few years after my brain injury, I went back to college and I did a course on counselling. They thought I wasn't reading the information properly. I was listening to people but taking too much of the information... *I was quite disappointed with myself.*"

At the end of this excerpt Rob makes it clear that these early attempts clearly had a negative impact on his mental well-being. My analysis of this suggests that when certain activities were attempted at an inappropriate time they had a significant impact upon Rob's mental state and therefore his identity (re)construction. Therefore, a flexible approach to rehabilitation which recognises its nuanced and subjective requirements would allow a nuanced and flexible engagement with rehabilitation experiences.

Rob told of the long lasting effects of positive interactions with rehabilitative services and the way that this has guided his beliefs as to the length of rehabilitation. Rob highlights the role that rehabilitation professionals played in the (re)construction of his bodily function after his ABI. However, what is not discussed is the ability of rehabilitation professionals to engage with other (non- impairment based) aspects of the (re)construction of his identity.

> "What was really good in rehabilitation was they found out that I was dropping my toes on my left foot and I was catching my foot on pavements and roads and falling over or tripping over, and so they made an appointment for me to go and see the mobility people at the mobility centre where they measured me up and fitted me with a foot splint which I use every day now, it basically keeps my toes up... I told them about it during a follow-up appointment... I don't really think rehabilitation after a brain injury ever ends... There are always things I could be doing that would improve my mobility."

Sam also recalls the long lasting effect that positive experiences in rehabilitation have had upon him. His experience is similar to Rob's in the way that he mentions the way that rehabilitation professionals were particularly effective at addressing impairment-based factors:

> "In rehabilitation I remember they had to teach me how to do things in the correct order, so I used to go with my occupational therapist into the kitchen and she used to watch me. She used to get me to make little things, not meals but just, I can't remember what I was doing really. But it's to do things in the correct order, so if you pull out some cutlery, and your pot and pan, you've got to put things back in the right places, in which order to put them

> really... it was frustrating at the time but looking back actually it was very helpful, I really did enjoy it."

These experiences are important as they demonstrate how both Sam and Eric comment on the way that they felt that rehabilitation professionals were good at addressing impairment-based factors.

Learning a "new normal"

The concept of achieving a 'new normal' is a notion which has great relevance to this chapter as not least it enables a greater exploration of what is meant by the word 'normal' when it is used in the context of the passing of time. For example, is 'the norm' a constant or does it fluctuate according to time, place and person? To begin to address this question I turn to the experiences of my participants. Engaging with participant experiences permits a greater understanding of the meaning of 'normality' by paying attention to how the participants have renegotiated their relationship with 'being normal' in the light of their experiences. For example, when describing the meaning of rehabilitation, Karl notes that:

> "I think rehabilitation is about learning a new normal. You don't ever recover, you learn new normals, you find different ways of doing things, easier ways whatever. You know what your limits are. If you went and ran, I don't know, say you can run 10 metres now, if you ran 30 metres it might knock you out for the rest of the day, so you know that you can only run 10 metres. So it's a new normal, but you never ever recover from a brain injury, because there'll always be things that bite

> you... that's just part of a critical illness, you just learn a new way, you have a new normal, but you have to learn what that new normal is."

When probed a little more regarding what he meant by the phrase "new normal" Karl explained that he was talking in general terms about the effect his impairments have had. He continued:

> "Well it's just that if you were born like it you wouldn't know any difference would you? You just – you learn for whatever physical disability or cognitive disability you have, you just – the human body's a clever thing for working a way around it and you work your way round don't you?"

Karl is referring to the way that a number of impairments can be integrated the overall construction of identity. For Karl, his identity has been malleable and has shifted to account for his ABI. Rather than becoming a passive victim of impairment(s), Karl suggests that you "lean a new normal" to account "for whatever physical disability or cognitive disability you have".

In the excerpt below, Sam shares his opinion regarding the individuality and unique nature of brain injury rehabilitation:

> "I think every brain injury is different, so [when rehabilitation ends] depends when that person seems to others that they're coping on their own okay, that's the main thing really isn't it? I guess that's when they've got to face the big world on their own, or have if they've

> got help or family, and then it's up to you really when you get. I sometimes, I bought the Sunday Express little brain training exercises and things like that, I think that's brilliant things like that, little mind games... There's also self- rehabilitation, if you, you've still got to train your brain. I mean I play mind games, and actually I think I have got, I do, do something my dad taught me, mind map. Mind map, I haven't even done a mind map before, but I do that a lot now. If I want to think of things I draw a mind map, I put the word in the middle, and I put links and, oh it's brilliant."

As well as highlighting the individuality of each person, Sam denotes the role outside influences play in achieving his "new normal". Importantly, Sam's use of the phrase "self-rehabilitation" denotes the way for him, rehabilitation which occurs throughout his life. My analysis suggests that this highlights the relevance of the concept of time, as Sam conceptualises rehabilitation as not being restricted to 'traditional' rehabilitative activities. He refers to activities that he does now, which highlighted the longevity of rehabilitation. Furthermore when sharing his thoughts regarding the meaning of rehabilitation, it is interesting the way he refers to "being normal" and the importance of "adjusting to things". 'Being normal' seems to refer to an impairment based view of disability which highlights the way that as an ABI survivor he is never going to be 'normal'. In contrast the idea of Sam having to "adjust to things" implies a situation where Sam has (re)constructed his identity to incorporate his impairments.

> "Rehabilitation is teaching to adjust isn't it? It's because brain injuries throw you completely off. So when you've had a brain injury you, I mean you get very lost, and rehabilitation is just trying to help you find yourself a little bit really, and learn to cope with society, and learn to cope with everyday doings. Like simple things, like cooking stuff and talking, or really basic things... I was in rehabilitation for about 3 months, and it didn't stop then. I went there for another year as an outpatient, but I'm still, it didn't fix me, I wasn't. After that I wasn't perfect *back to normal*, I'm still a person with a head injury at the end of the day, *so I still have to adjust to things*."

In a similar way to Karl's thoughts concerning rehabilitation, Sam is conceptualising his rehabilitation and the (re)construction of his identity as a complex process whereby he has "to adjust to things". Sam considers rehabilitation as being something that is unbounded by time and place and which is dictated by his ability to adjust, rather than an activity which is time-limited and is relevant only in a period of his life. Rather than referring to the inescapable 'reality' of brain injury, this section has been directed towards exploring the ways that the participants integrate their impairments into their unique lives. In adapting their actions and behaviour to compensate for impairments, the participants are giving examples of where they are (re)constructing their identities.

In the way many of the participants construct their idea of normality to incorporate their impairment(s), the data has particular significance

to debates which refer to the identity of disabled people. When analysed according to a 'rhizomatic' and 'nomadic' framework, these experiences demonstrate the way in which the participants' lives have been altered significantly, but crucially not ended by their ABI. This clearly contributes to a discussion regarding the construction of identity of disabled people. As such, the data in this section has highlighted the ways that my data analysis has helped me understand the role of the concept of 'being normal' in future 'imaginings' in the (re)construction of identity of ABI survivors.

The response of others in society seemed to be of concern to my participants. Many of the difficulties that the participants experienced appeared to be due to the negative way that they felt that they were regarded by others. This dictates that the perceptions of others are important in the construction of the identity of the participants. I now turn to an empirical demonstration of this.

Attitudes toward ABI survivors

The discussion throughout this thesis concerning the heterogeneity of ABI dictates that there can be no single impairment that indicates the presence of ABI. Despite this the participants cited the way in that they felt they were uncomfortable in certain circumstances due to the way that they were perceived by others in society. An example of the way that the attitude of others in society seemed to concern my

participants is provided by engaging with this excerpt from a conversation with Eric:

> "...I do get angry a lot about people's attitudes towards brain injuries...That's not my problem. But I don't know why people- people have got to judge, really..."

Eric continued to expresses his frustration when describing how he travels around his local area:

> "People look at you and do judge. You know? They think, well, you've got a bus pass. Why have you got a bus pass. I had a brain injury. I can't stand very long because I feel faint and people do judge and people seem to, like, talk about you... Maybe I'm paranoid about it, like. But some people have said on occasion, oh, he doesn't need a bus pass. He's all right. Nothing wrong with him, he can walk."

Sam talked of how the attitudes of others towards him do not seem to depend on the position that the person occupies within society. Sam referred to an interaction he had with a nurse at his local hospital:

> "...I went to hospital, my local hospital once last year, because a cut from my thumb was sore... I went there for stitches, and then I said about my brain injury. And the nurse says "oh, I thought you had something, I thought it was something like a brain injury...I knew you had something...really when you see somebody you've got to tell somebody you've had a brain injury because we won't quite know what's *wrong* with you..." (my emphasis added)

When asked how this made him feel Sam commented:

> "...it was upsetting. When she said I knew there was something about you, she seemed to make it clear that they can just sort of tell I'm different, and it was a bit of a weird thing to say, and it upset me. .."

The discussion of this experience highlights the effect that everyday interactions have had upon Sam's identity as he reports feeling "upset" after this incident. This experience therefore demonstrates the way that identity is affected by such interactions. This section highlights the way participants were uneasy about others' opinions of their impairments and towards ABI survivors in general. Discussions surrounding 'psycho-emotional disablism' (Reeve 2002) examine in more detail the way that these interactions play an important role in shaping the identity of disabled people. This is important as it reinforces the negativity that my participants experienced as they were (re)constructing their identities. Despite the effects of these interactions once again my participants seem to demonstrate agency in their responses to such labelling. In the following section I detail some of the ways my participants seemed to side-step and (metaphorically) dance around the judgements of others within society.

Demonstrating agency and resistance: The brain injury dance

In this section, I seek to represent instances where my analysis suggested that the participants demonstrated agency and resisted the

attempts at static labelling that were reported in the above section. An example of this resistance can be found in the way Rob has integrated his impairment into his conceptualisation of his own identity. Rob spoke of how he has learned to not allow the views of others to impinge on his self-image.

> "...Over the years, since my brain tumour, the cause of my left-side disability, I've come to terms with it... It makes me feel awkward, and why can they not just give you five minutes of their time to ask you what's wrong or maybe speak to you about your injury or why you're walking instead of- instead of staring at you and thinking you're not normal?.. I know people look at me and stare at me because I may walk funny, I don't really care though... in my own head, that's who I am now..."

Similarly, Sam spoke of how he comes to terms with the way that others view him:

> '...I don't care how other people view me....because you're your own person and if they don't like you they don't like you, it's simple as that...

Karl talked of the great importance he attaches to "feeling normal".

> "I just feel a *normal* person. I'm just a *normal* person. Perhaps a little bit more paranoid because of other things that go on in your head but, you know, there's no judgement- they can't see it so as long as they can't see it, I'm happy."

Interestingly Rob spoke of the way that his ABI has changed his own conception of what is 'normal'. Towards the end of this excerpt, Rob hints at his eagerness to try and use his experiences of ABI to change others' conception of what it means to be 'normal':

> "...In ten years from now I would like people to see or- Yes... people to see disabilities as normal... I think I would like to be a spokesperson for certain disabilities and illnesses...because I think people need the help with it. And it all comes back to learning to live with your illness or disability and once you've come to terms with it, you're more able to cope with it and deal with the issues. I want to give something back to the country that saved my life..."

The eagerness that Rob displays in his determination to change others' perception of 'normal' is clearly an important part of Rob's life and a constituent in the (re)construction of his identity which demonstrates his capacity for demonstrating agency and resistance to what he thinks society deems to be 'normal'. This excerpt also relates to the way that the participants wanted to be seen as being capable of being 'useful' citizens. This is a theme which appeared fairly commonly throughout my interviews.

I have discussed situations where participants discussed labelling as a negative part of their lives, but according to other experiences it can also be seen as a positive aspect. For example, in one interview in particular the participant talked of how being labelled as a brain

injured person helped him secure council accommodation far quicker than he otherwise would have.

> "I was living with my sister at the time in a house, and I was struggling with the stairs. Somebody told me to say it actually, and I said I am disabled, and I do find it very difficult to go up and down the stairs, and they highered my band. They highered me from bronze or was it silver, bronze, to gold, they put me up to gold. And then a place come up right close to my mum's, so I thought that was really great, so yes then I applied, and I got it."

Crucially Sam notes how being a brain injured person worked to his advantage. This is clearly an important part of his identity. It should be made clear that all of my participants were interviewed between three and thirteen years after their brain injury. It is highly probable that the issue of time has proved to be important in their formation of self-identity. An example of this could be with the strategies they have developed to incorporate the reactions of others in society into their identities. In the following section, instances where the participants took an uncertain gaze into the future are explored.

Employment: The "hopes" and "maybes" of the future

The negotiation of future employment was one area that was particularly relevant during my analysis of the interviews. It is perhaps when considering employment that the realisation of the longevity of rehabilitation may be enabled. When concerning employment, Wayne talked enthusiastically about his current job at the Co-op. When asked

questions related to his conception of self-identity in terms of his rehabilitation, Wayne described how important his work was in his rehabilitation. At the time of interview Wayne had recently managed to secure a job. Having a job was clearly important to Wayne. In terms of the importance of the notion of time in his rehabilitation, the possibility of future employment and how future employment was 'imagined' at the time of his ABI was not something that Wayne mentioned. As referred to earlier in this chapter, the main focus of early interactions seem to be on what Wayne may have 'lost' rather than what they may be capable of in the future. When asked about how his current job makes him feel, Wayne responded:

> "Well you know to be honest I, it makes me feel fantastic because I was absolutely petrified going in there because working at the British Red Cross shop that's charity, that's a charity shop. You can work at your own pace, you can do whatever. This supermarket job, this is the real world you know this stock needs to be put out. You don't do it at your leisure. You know what I mean? This is, they are counting on you to get this out. You know what I mean? You know you have to, you know you have to be so point of everything that you do because you know they need to make their money and if you are slacking then that's not good you know and you have just got to remember where things are. So you have got to help customers you know and I was nervous and everyone has just opened their arms to me, everybody's been so helpful in there. The managers love me and it's just really nice to be appreciated for what I do."

Wayne also spoke of how he "loves to keep busy" which is something that employment provides to him. Wayne also provided a stark

reminder of the unique and heterogeneous nature of brain injury, when he commented that:

> "That's just me. Well, you see, it's difficult to say anything that will be right for everyone, because it really depends on the brain injury. You know?... And it depends what work you do. But I overall I would advise to get out there and start doing something, whether that's paid or voluntary."

In addition to the importance of future life events in the (re)construction of Wayne's identity, Wayne's idea that each person is unique and an individual and every person is different is evident in much literature concerning ABI (Gelech and Dejardins 2011; Sherry 2006; Lorenz 2010). In addition this notion was reinforced during a similar conversation with Eric. Some years ago, Eric decided that he would try and go back to work. He got a job as a road sweeper in the local area. He talked of how he really struggled to keep up with the demands of the job.

> "I was working all over the city and the pressure I got from it all was terrific. You know? You couldn't believe the stress I was under. I was trying to sweep roads, pick litter up, clean the streets, basically, and the roads – the side of the road. But the roads were so long, you've got a long road but you've got to do both sides... So, I went up and down and then I've got to go to other places and different things, a van will pick me up and take me somewhere else and then tomorrow I was somewhere else, and I just couldn't cope– my situation got worse and it really got me down and then you get the complaints in because you haven't swept- you've only swept up half of the side of the road, but you can't sweep it all up in the day, because you haven't got the

> time to do it. And then somebody moans because you haven't done it and then you get complaints and then it's- It puts a lot of pressure on you because you feel like a failure, you know?"

Eric eventually had to give up the job, and at the time of the interview he had been out of work for some time. Eric felt that he could no longer manage with the pressure of work. Eric spoke of how he sought help, but he felt that none was available so long after his brain injury:

> "I just couldn't cope. [I] took time off work, went to occupational health and they signed me off for a bit and then they come to a point where they're looking at other things I can do in the council, that may take the pressure off me, but there is nothing I can take to take the pressure off me. There's no part-time work or anything. There's nowhere I could- No help, basically."

Considering his willingness to try and modify his career plans following his ABI, Eric's assertion that there was "no help" adds further weight to the suggestion of more long-term support for ABI survivors together with contributing to an understanding of what a fully 'rehabilitated' body may be.

Eric gave a strong indication that he required some help in deciding what to do in the future. Rather than wanting to forget about work, Eric was keen to reengage with a different type of work in the future:

> "If I could get back and do some charity work- that would be great... whatever charity, I don't mind... I would like to work with things that are associated with me – either mental health issues or brain injuries. Some charities like that. So I'm putting back into something that I experienced and something that I have used, like. You know?.. And it's giving something back but also I'm going to get something out of it as well. I'm going to learn, hopefully. People say, oh, some people are too old to learn. Like if you're whatever age; if you're 32 like me or whether you're 78, it's always a chance to learn. There's always learning, and I think it's good."

Sam had been working voluntarily at the Citizen's Advice Bureau for approximately one year at the time of the interview. Although he is currently working on a voluntary basis, Sam talked enthusiastically of how he wanted to gain paid employment in the future to provide a sound financial support for his family:

> "In a few years, I really want to get paid work. I would like to support my family, that is the whole object, that's why I want to work really. I don't want to work just for working though, I want to be able to support my family, but it will have to be something not too hard labour really because I get tired really easily, I have got to work with what I have got really, so I mean I am doing phone advising at the moment. I advise people on the phone and that is really rewarding because I have helped so many people, I have even helped a police officer that was in some trouble, so he was really thankful and that was really nice."

Notably Sam talked of how he is performing well in the job and is enthused about his future work there:

> "The funny thing is before my accident, when I used to go to college and school I was always the one at the back not paying any attention, and now I've got a really low attention span, but at Citizens Advice I'm the only one on learning journal 2, so I'm ahead of everyone at the moment, so that's really good..... I was speaking to my boss about a month ago about it, and she was 'Yes well you are doing really well, and if you keep this up for another year, go downstairs and do face to face advising. Do that for a year and then you will be ready for money management training' which is free but it pays 29 grand a year, so *hopefully, maybe.*"

This excerpt provides another example of the way that Sam is (re)constructing his identity following his ABI. Sam's propensity for future work is clearly important in the (re)construction of his identity. It is also noteworthy that Sam talked of some of the ways he feels he has improved his willingness to engage in academic work since his ABI. When Sam talks of possibility of his voluntary work leading towards permanent employment, the words 'hopefully' and 'maybe' seem to neatly capture the unstable, yet optimistic way Sam envisages his future.

In contrast to the experience of Sam, Karl talked of how before he had a stroke in 2010 he used to work in a factory making aeroplane parts. Karl spoke of how he had critical illness insurance cover prior to the stroke and did not have to work currently. Karl mentioned how his occupational therapist took a fair bit of time to understand this.

> "At first the OT kept going on about how I should try and go back to work. It took a while for her to understand that I had no intention of going back."

This is important as Karl is discussing the way rehabilitation professionals advised him on his career path. Karl's experience of the attitude of his occupational therapist demonstrates where the rehabilitation professional has (seemingly) not engaged with the factors that were important to him in the (re)formation of his identity and with particular significance to this chapter, the rehabilitation professional had not investigated what Karl envisaged for his future life. Despite not wanting to go back to the same job, Karl told of how he enjoyed engaging with local charities and helping people on a voluntary basis:

> "I'm looking at- I've just been speaking to somebody at a charity for homeless people now... I went there last Wednesday. I went there to the homeless centre and I put my name down to do some voluntary work just to get my foot in the door, which will hopefully lead to not paid work but being able to do a bit more with the homeless people, because I'm happy to give my time for nothing to do something that I actually enjoy. But if it meant going back to doing a job that I didn't enjoy, not being paid, then I wouldn't do it. And it's because I- that's something that I would like to do – work with homeless people."

Karl continued to talk about the future and how he had already considered his future life:

> "I am desperate to get an allotment or something... I'll also have my voluntary work because it's something I can choose what I do. If I like it then I can carry on with it; if I don't like it I don't have to carry on with it. I can go and find something else that I do like doing. Eventually the kids will be big enough to look after themselves. It will just go back to like it was before we had children."

Concerning his experiences as they relate to issues of employment, Rob was currently working at a local supermarket. He had worked approximately 16 hours a week for the past few years. Rob talked of how he was helped to get into work and spoke of the way he has enjoyed his work:

> "If you have the ability to do it, I would say do it. It gets you out of that situation where you may be stuck at home all day. I was helped a lot... There are schemes, disabled schemes at work places where you can do certain hours a week."

The uncertainty and unpredictable nature of the world of employment is perhaps best summed up by Jason. At the time of the interviews Jason was taking exams that he hoped would lead to him being able to be a Gymnasium instructor. However, towards the end of my involvement at the support group, Jason was no longer a regular attendee at the centre. I found out from one of his peers that he and his wife had just begun to run a local car wash and he no longer had time to attend the group. Even at the time of the interviews this turn of events was unknown to him and also to me.

Is the future so bad?: "Nine times out of ten I'm a happy person"

It has been stated that disability in general is all too often depicted in a 'tragic' (Oliver 1990) or 'melancholic' (Roets and Braidotti 2012) way. This chapter has sought to explore time and particularly the future. Engaging with the experiences of the participants as they relate to time has provided an opportunity to theorise their experiences in a progressive way. Within my conceptual framework an affirmative way of conceptualising the lives of the participants is important. Therefore, within this closing section of the chapter, I draw upon the empirical evidence from my interviews to challenge this notion and as such recount some of the positive tales the participants had to tell about their unfolding futures.

Although at first glance Rob's experience may seem to reify the melancholic portrayal of disability, this excerpt neatly captures the way that my participants did not view their brain injury in this manner.

> "Before my brain injury I was fit, I was working as a Chef, about 40 hours a week if not more, I was in a relationship, a happy relationship and life was great. Now I have got myself back through rehabilitation, I am back at work, I still lead a good social life, I go out and meet people who have been in the same situation as me... I have come to terms with my illness and I have learned from other people how they have come to terms with their illness, and I think it makes us all stronger in our lives... brain injury I would see someone who was disabled and maybe think, well I

> don't really want to spend time with them, whereas now I spend most of my time with disabled people, so it is nearly 100% switch around from where I was to where I am now."

During this interview Rob seems to prefer to focus on the positive aspects of brain injury and talks of the ways he has improved as a person following his ABI. It is interesting how Rob conceptualises his brain injury in terms of what it has provided, rather than what it has taken away. He was not alone in this. When discussing his voluntary work Sam commented:

> "I come home sometimes and I feel actually my life is not that bad really, because I work in citizen's advice the people that phone up have such big problems, you know, I know I have had a brain injury but I have learned to not... I was only saying this yesterday actually, I have learned since my brain injury, just to deal with my little problems and ignore them almost and just focus on the good things in life really... Overall, I would say, 9 times out of 10 I am a happy person, I am happy generally."

Karl talked of the way he feels that brain injury survivors are able to draw great strength from their experiences.

> "When a person has had a brain injury you will find that whilst they aren't better they are certainly stronger, because takes a hell of a lot of guts and determination to try and beat what you've been left with, because that's what you end up doing, you end up trying to beat it don't you? You don't succumb to it."

Wayne appeared to be incredibly proud of his achievements. Initially, he talked of the difficulty and the pain that the anniversary of his brain injury brought. However, he has now reached a place where he sees the day as a celebration rather than a melancholic event:

> "I had my accident on the 23rd December and it was raw for a few Christmases as you can imagine...You know when that time came. It was hard, but now that I have accepted it and moved on everybody else has and we just celebrate it in a positive way rather than looking at it a negative way. We don't think about that day anymore, well I don't and we just enjoy Christmas... Well, with all I've achieved, I am the proudest man on the earth, with everything I've overcome. Well, what I've done. I'm just so proud."

In a discussion with Karl about his life in relation to his overall (re)construction of identity after ABI, he sums up the way he has integrated his impairment(s) into his identity (re)construction. In so doing, Karl demonstrates the importance of every-day experiences in the (re)construction of identity following ABI.

> "...But if sometimes you don't make a joke out of things then what do you do? It's like me, I'll knock drinks over for a pastime...And quite a lot of people get angry, like really frustrated, but what can I do? I didn't see the glass. I can't see the glass there so I knock it over you know what I mean? And it's like, what do I do? I get angry with it or I laugh at it and now I just laugh at it, because it's just – well I don't know, it's not funny I guess...but it's just a light way of making good of a bad situation..."

Karl does not appear to have fundamentally changed his identity in response to his brain injury. Rather he appears to have integrated his impairment into his overall identity. After engaging with the experiences of the participants, an impression of the way their ABI has impacted on their every-day life can be gained. The way identity has been (re)constructed for Karl, is summed up when he talked about an incident that occurred when he returned to the family home after his stroke. Karl talks of how his cognitive impairment impinged on his ability to perform every day, seemingly mundane tasks, such as washing his clothes. Karl said of his experience:

> "...I suppose it's funny when you look at it, it must've been funny in a way for me to say, "What the fuck's the washing machine do?"... If you don't laugh you're going to cry. That's the sort of stuff you've got to deal with after a brain injury..."

This experience encourages a sophisticated engagement with the every-day activities of an ABI survivor and is intended to encourage deep thought rather than relying on seemingly brute facts and/or 'realities' in the lives of ABI survivors. The existence of Karl's cognitive impairment may initially seem obviously 'real' and therefore his impairment is undoubtedly in existence regardless of his daily activities. This quote also highlights the importance of time in the construction of identity, as this was only a temporary difficulty for Karl, meaning that the 'reality' of impairments can fluctuate according to time. Karl's use of the washing machine highlights the importance of integrating impairment into the changeable social context of an ABI

survivor's social world. This is a theme that re-occurred throughout the interview excerpts that form this chapter. I now briefly return to literature which explores disabled people's lives to demonstrate how the data in this chapter can be situated within this literature.

Situating this chapter within literature which seeks to explore the relevance of the future in disabled people's lives

This chapter explores the experiences of the participants as they are related to time and in particular the possibility of future life events during their rehabilitation following ABI. With regard to the importance of time it has been stated that:

> '... unless we develop concepts of time and duration that welcome and privilege the future, that openly accept the rich virtualities and diverging resonances of the present, we will remain closed to understanding the complex processes of becoming that engender and constitute both life and matter.' (Grosz 1999: 16)

A future-orientated framework such as a rhizomatic and nomadic framework would accept that its subject is ever moving and becoming (Goodley 2007a, Goodley 2007b). Such a framework has been advocated for use in the consideration of the provision of inclusive education (Goodley 2007b). With reference to ABI rehabilitation the use of such a framework would therefore acknowledge the possibility of future growth and uncertain development. Considering this it would seem sensible to suggest that a framework which embraces the

possibilities of impairment would be most suitable for use in the rehabilitation of ABI survivors as they grapple with the complexities of identity (re)construction. I have drawn on the experiences of the participants in order to explore how their every-day activities interact to determine their identities. I have explored aspects of their lives which have included examples of the way that the various impairments have been integrated into the lives of the participants. For example, when Karl explains how he had difficulty working the washing machine, the time limited 'reality' of his impairment was relevant to him at that time, but is now no longer a problem.

In-keeping with the notion of the future and identity (re)construction Roets and Braidotti (2012: 175) call for a disability studies which is a 'project of affirmative politics that celebrates embodied diversity'. Furthermore, Roets and Braidotti support a configuration of the disabled body that:

> '... brings the impaired subject back into play as a moving set of differences, that capitalises on the energies of a heterogeneous ... multiple and nomadic subject with bodily rupturing roots that transforms and reconfigures the self in a politicised and anti-essentialist way' (Roets and Braidoti 2012: 168)

This assertion has particularly resonant implications for the practice of ABI rehabilitation. In short, embracing the notion of the future and thinking of ABI rehabilitation in a rhizomatic and nomadic way

leaves room for the transformation and reconfiguration and also the (re)construction of identity of a brain injury survivor. The idea of impairment(s) changing over time prompts a conceptualisation of the body and impairment which embraces this. However, this could provoke a singular focus on research which is based solely upon the impairment factors in the lives of disabled people. This has been said has been said to homogenise the experiences of disabled people and reduce their identity to a single determinant (Gelech and Dejardins 2011; Richards 2008). Therefore, it is important to note the role of impairment(s) in identity (re)construction, with reference to how impairment(s) may change over time. In exploring the daily-details of the lives of the participants, in this chapter I have sought to engage with both impairment and social factors that relate to the notion of time in the (re)construction of identity after ABI.

Conclusion

Within this chapter I have framed the experience that the participants shared with me regarding their opinions on the length of rehabilitation. I have demonstrated that future events such as having children have a profound effect upon identity (re)construction. This then, questions the ability of short-term rehabilitation interventions to engage with the identity of ABI survivors. I have also addressed the experiences of the participants which may question the importance of normality in contemporary society. The individuality of brain injury rehabilitation is overwhelmingly evident throughout this chapter.

However, the uncertainty that surrounds the future is the main concept within this chapter. As well as raising questions regarding the way we theorise brain injury survivors' experiences and rehabilitation in general, this chapter is intended to have practical implications in that these experiences could be used to maximise the efficiency of rehabilitation interventions. In this chapter I have focussed on the periods of my participants lives which the neurological rehabilitation process could not envisage.

Within debates concerning the identity of disabled people it has been asserted that when the lives of disabled people and the significance of disabled bodies is scrutinised in detail then the reality of disabled bodies soon becomes questionable (Campbell 2009). My intention during this chapter has not been in any way to dis-embody the lives of my participants, but to simply offer a way of framing the experiences of ABI survivors, which seeks to highlight the uncertainty of both social and medical determinants of the (re)construction of identity; one which is drawn from a close engagement with the daily details of ABI survivors.

The empirical data within this chapter which emphasises the fluidity of identity seems to align with the thoughts of McGuire (2010: unpaginated) who notes that:

> 'disability marks the body in ambiguous ways- it appears and disappears, is noticed and is hidden-as we move very different physical and

> social spaces and as we find ourselves in different political and historical moments.'

In the final chapter I use the empirical data, together with my personal experiences of ABI and the existing literature to highlight some important areas for reflection that this study has indicated.

Chapter 7 Critical reflections

In this thesis I have explored the (re)construction of identity following ABI. This has included an investigation of some of the every-day activities of the participants, a consideration of the relevance of the notions of dependence, independence and interdependence in the lives of ABI survivors and analysis of the importance of future life events of ABI survivors. This study has critically interrogated the (re)construction of identity after ABI from the perspective of the ABI survivor. Rather than focus on the impairment(s) of the participants I have highlighted their experiences of their identity (re)construction following their ABI. I have used a critical social scientific analytical framework which has been used as a framework in which to analyse the participant accounts of their identity (re)construction after ABI. Being an ABI survivor myself has had some important method/ological consequences. These have been discussed throughout the thesis and further exploration continues below.

Within this chapter I review the questions this research sought to explore and in doing so highlight some of the key themes within this thesis. This discussion leads onto an explanation of my unique contribution to knowledge. Following this I will critically explore the ways in which I feel a closer engagement with critical social scientific

theory can add to existing debates surrounding ABI with particular reference to the rehabilitating body. In order to reinforce my assertions I refer back to some key literature and seek to discuss how my study is located in the ongoing debate surrounding disabled people's lives in an ever-changing neo-liberal society. This thesis has also considered the method/ological complexities of research. To this end I offer some reflections on both the method and the methodology of the thesis. This study has important practical implications for researchers, practitioners, family members of ABI survivors, ABI survivors themselves and others. As such I highlight some areas which may be of particular practical value. Following this, I highlight some of the limitations of this study. I begin with an overall review of my thesis by returning to my research questions.

Returning to the research questions

The substantive issues which this thesis has sought to explore can be noted by referring back to my overarching research questions. To recap my research questions sought to explore the (re)construction of identity after ABI.

More specifically this thesis sought to investigate two issues:

(i) The ways in which the study of identity (re)construction after ABI can inform debates surrounding the identity of disabled people.

(ii) The ways in which the experiences of the (re)construction of identity after ABI can add to the existing literature regarding neurological rehabilitation following ABI.

Due to my personal relationship with ABI, the final question which underpins this thesis is method/ological in nature and seeks to investigate how my identity has influenced this study. My final research question was:

(iii) In what ways has being an ABI survivor and volunteering in an ABI support group impacted on the research?

This is further explored in a later section regarding my method/ological reflections on this thesis. I now follow up my discussion of the research questions by revisiting the themes that emerged from the data, thus highlighting how this thesis has contributed to the body of literature exploring ABI and ABI rehabilitation.

The main themes within this thesis

This thesis has explored the every-day details of the lives of ABI survivors. The participants had many experiences to share regarding the seemingly mundane day-to-day details of their lives. During analysis, I noticed how these occurrences play an important role in the identity (re)construction of the participants. I conducted a further investigation of the experiences of the participants as they navigate

through the social world. The themes of dependence, independence and interdependence and time, were the two main themes that emerged from my analysis of the data. Some of the experiences of the participants reinforced the notion that their lives are dictated by the presence of their ABI and associated impairments. Meanwhile, other experiences point towards the way that label of 'brain injured person' rather than the 'reality' of the ABI itself seems to dominate their experiences of identity (re)construction. An example of this is evident in Sam's experience of his encounter with a nurse who questioned him for not disclosing what was 'wrong' with him. Given the dominance of medical literature regarding ABI, it is all too often taken for granted that ABI is simply a medical issue which is wholly explained by medical 'deficits'. I have sought to demonstrate how thoroughly investigating many more aspects of the lives of ABI survivors can demonstrate the r(e)construction of identity following ABI in a thorough and more comprehensive way.

The relevance of dependence, independence and interdependence in the lives of ABI survivors

The notions of dependence, independence and interdependence were particularly relevant in my data. There are times where the relationships of the participants seem to be characterised by their *dependence* on others. This is particularly evident in experiences of early rehabilitation where the participants were fairly reliant on

nursing staff. Meanwhile, as their rehabilitation continued, there were instances where my participants were no longer reliant upon the same levels of care. Furthermore the participants talked enthusiastically about how they could help others. For example Wayne talks of the satisfaction he took from his voluntary work. Rather than adding to debates surrounding dependence, these experiences demonstrate how the identity (re)construction of the participants suggests that in some situations they are dependent on help, and in others they are capable of providing such help. In short help, care, support and so on are changeable features of their lives which often evidence notions of reciprocity, rather than polarised notions of care receiving versus care giving. This is an important departure from literature which conveys that rehabilitation is considered a practice which promotes *independence*. This data demonstrates the relevance of the notion of *interdependence* in the lives of the participants. Notions of dependence, independence and interdependence were all relevant in my study, and dependence in a particular time and place (for example in a hospital or in early rehabilitation) did not preclude the ability for the participants to provide help to others at other times and places. This evidence seems to suggest the fluidity and changing nature of the identity of ABI survivors.

In addition to highlighting the flexible nature of care relationships the empirical data also suggests the role of non-organic objects in the (re)construction of identity following ABI. An example of this would

be the way Rob talks about how his nephew views his walking aid. From this experience I would suggest that Rob's nephew regards Rob's walking aid as an integral part of Rob's identity. Consequently, this experience denotes the role of others (both living and otherwise) in identity (re)construction and seeks to encourage further debate about whether lives should be considered in isolation. Overall the data highlights the situation specific relevance of notions of dependence, independence and interdependence in identity (re)construction following ABI.

The relevance of time

The realisation of the importance of future in the (re)construction of the identity of the participants is the second over arching theme that my analysis indicated. I have explored how notions such as the use of power in rehabilitation settings have impacted on the lives of my participants. An example of this is provided when I analyse the way several of my participants remember interactions with healthcare professionals, and the negativity that these interactions conveyed.

Furthermore experiences of future and unpredictable events (such as joining a writing group) are presented. I argue that these experiences are unforeseeable and highlight the importance of the consideration of time in the identity (re)construction process following ABI.

Unique contribution to knowledge

Research related to ABI and ABI rehabilitation has been conducted predominately within medical parameters (Hammell 2006; Lorenz 2010; Sherry 2006; Stewart 2014). In suggesting a critical, contemporary social scientific theorisation of ABI and ABI rehabilitation I have sought to depart from this tradition of relying on medical 'facts' by representing the every-day experiences of the participants to stimulate discussion regarding the (re)construction of identity following ABI. I have also encouraged debate surrounding the appropriateness of the notions of dependence, independence and interdependence with in the lives of my participants. This thesis has sought to engage with the unstable futurity of my participants and in so doing suggested the becoming-ness of their rehabilitating bodies. I have used this empirical data in conjunction with a critical, social scientific analytical framework to enact an exploration of the identity (re)construction of the participants.

Another way that my thesis adds to knowledge regarding ABI and ABI rehabilitation is clear when engaging with the method/ological dimensions of this project. To recap, I am an ABI survivor and have also had approximately two years' experience as a student physiotherapist. Together with my newly acquired skills in social science research, I have explored the identity of ABI survivors and indeed ABI and ABI rehabilitation from a three-dimensional and

unique perspective. I am able to explore the lives of ABI survivors as a trainee clinician, turned ABI survivor, turned social researcher. This has raised some important methodological considerations which are further explored in a later section. However in the following section I explore some of the substantive themes that this thesis covers.

Theorising the lives of my participants

My research is driven by my overall research questions. I wanted to provide thick, detailed responses to these questions by asking participants questions related to their everyday lives. The data that denotes the relevance of notions of dependence, independence and interdependence was gleaned from a wide range of questions which were completely unrelated to the themes of this chapter. In addition, many participants had informally talked about how they thought a thorough consideration of the future was something that was missing from their rehabilitation prior to the interviews. Furthermore this seemed to be important in the study of identity (re)construction after ABI and is something that was both absent from the literature exploring the lives of ABI survivors and something I felt was missing from my own personal rehabilitation. For this reason, I was determined to include this in the thesis. However, I found it difficult to stimulate participant responses that were related to their future, without asking participants direct questions regarding this. I combated this by choosing to interview participants who had already navigated the early stages of the rehabilitation process. Due to this I was able to

gain certain insights relating to how their rehabilitation was 'imagined' by asking questions about their early experiences of rehabilitation as well as questions related to their every-day lives.

In order to provide a backdrop for the empirical data of the thesis, I have critically evaluated literature pertaining to some important and current debates in the neurological rehabilitation process. This literature was predominantly medical in nature and sought to explore a number of clinical issues. This included a critical exploration of issues such as a multidisciplinary teamwork and goal setting. These are indeed important debates in the neurological rehabilitation process but are not reflected in my empirical data as my research questions sought to engage with the lives of ABI survivors.

When considering the overall aim of this thesis is to explore the (re)construction of identity following ABI, this demands that ABI is studied from a long-term perspective and highlights a clear 'gap' in current knowledge. Thus, much of chapter two comprises a review of literature related to the construction of identity of disabled people. Longer-term issues such as the integration of impairment(s) into disabled people's lives become important in a critical appreciation of identity (re)construction after ABI. It therefore is necessary to widen the scope of enquiry to include literature which is related to 'disability identity'. Only after an appreciation of such concepts can a

framework which seeks to explore the (seemingly mundane) long-term, daily details of the lives of ABI survivors begin to be developed. The analysis of seemingly unimportant experiences (such as the reactions of others, when Eric gets on a bus) prompts a wider discussion regarding the labelling of ABI survivors, the significance of impairment in the identity (re)construction and so on

Although they are extremely rare, there have been a few studies (Lorenz 2010; Sherry 2006; Stewart 2014) which seek to explore brain injury from the perspective of brain injury survivor rather than seeking to increasing efficiency of the neurological rehabilitation process from a clinician's perspective. My study builds upon these studies by using the experiences of ABI survivors to firstly explore the identity of people who have sustained ABI within the contemporary social arena. Secondly I have sought to enact a critical interrogation of the neurological rehabilitation process. Within the scope of the second aim is an attempt to transfer the critical gaze away from my participants' lives (Campbell 2009) and onto the institutions which are designed to make their lives easier, without ignoring the daily details of their lives. In order to analyse the every-day experiences of my participants, I used a critical social scientific framework that was inspired by the writings of Deleuze and Guattari (1987/2004) and Rosi Braidotti (1991, 2003, 2006, 2011a, 2011b, 2013). In the section below I explore how the use of this framework has permitted a sophisticated interrogation of the research questions.

A critical conceptual framework

My conceptual framework for this study was heavily influenced by the writings of Giles Deleuze and Felix Guattari (mainly *A Thousand plateaus: capitalism and schizophrenia* 1987/2004) and Rosi Braidotti. The use of the writings of Deleuze and Guattari and Braidotti in the analysis of the experience of my participants has suggested a consideration of the lives of my participants as a journey of perpetual becoming; lives that refuse to lie still and accept their fate. It is a journey that emphasises the reciprocity of care and support. Being an ABI survivor does not indicate that the participants are always in receipt of care and support. Rather, my analysis of the data promotes a close and at times, overlapping nature of care and support in the lives of ABI survivors. It is a mobile concept that varies in nature depending on situational circumstances. Sometimes the participants are dependent on other people or objects, and sometimes those people and objects are dependent on the participants. In short, the use of the concepts of the rhizome and the nomad can be used in directing us towards viewing life as if it was not a linear, predetermined entity with a definite 'end in sight', but instead as a journey with unforeseen checkpoints along the way.

For the participants, sustaining ABI was without doubt an important checkpoint in their lives. An analysis of the (re)construction of identity after ABI has indicated that it is indeed a checkpoint, rather

than an end point in their lives. Rather than view the identity of ABI survivors in a fixed, static way where opportunities for future growth are not permitted, an acceptance of the unpredictability of the future may well enable an approach which celebrates the uncertainty and changing nature of the future.

When applied to my research, these concepts can be used to question the classification of any person in terms of a single facet of identity (such as by their ABI). An example of this is provided by the way the participants feel they are labelled as 'damaged' by people in society. The use of my analytical framework has allowed me to appreciate the 'nomadic' ability of people, where the static, fixed vision of being is replaced by a dynamic, adapting vision of 'becoming' (Braidotti 2003, 2011a, 2011b; Deleuze and Guattari 1987/2004; Roets 2009). The notions of becoming or nomadism seem to carry particular significance concerning the lives of those who acquire an impairment since the focus is shifted away from what they may *be* and shifted towards a vision of potential and what *the future may hold.*

When noting the every-day activities of the participants such as walking through the street in terms of the contribution of these activities to identity (re)construction, my analytical framework has allowed me to demonstrate where the participants have challenged normative ideas of the dominant, able-bodied citizen. This notion is

neatly captured by the way several of the participants note their lack of interest at how others in the street perceive them. Furthermore in using my analytical framework to help me to understand the connections the participants make through their lives (for example with technology), and by transferring the focus to the future (for example with a consideration of future employment), an unpredictable vision of possibility has emerged. This is in stark contrast to the traditional way that the lives of ABI survivors are traditionally viewed as tragic lives where personhood has been forever lost (Collicut Mcgrath 2007; Gelech and Desjardins 2011; Lorenz 2010; Medved and Brockmeir 2008; Sherry 2006).

In this thesis I have explored how an engagement with identity (re)construction of ABI survivors can inform wider discussions of the identity of disabled people. The empirical data that I present in this thesis emphasises the unpredictable nature of my participants' lives. For example, some have become parents since their ABI, some have not. Some are employed, some are not. Some enjoy outdoor activities, some do not. This data would appear to reinforce the assertion that celebrates the fluid and wholly malleable formation of the identities of disabled people (Goodley 2007a, 2011; Roets 2009).

The accounts of my participants also enabled me to investigate their perceptions of neurological rehabilitation. The appreciation of the

fluidity, changeability and unique nature of their lives appeared to be absent in the accounts of my participants regarding their rehabilitation. In analysing the accounts of my participants, it became clear that many seemed to emphasise the way that their lives seemed to be seized from them by rehabilitative practices (eg. you *will* return to work, you *will* be independent). Crucially, in interrogating neurological rehabilitation, I have been able to capture some important moments of resistance among my participants such as their use of technological devices in their every-day lives. If the thoughts of Deleuze and Guattari are consulted, on the construction of all things it would appear that:

> '...every concept is already a multiplicity, every book a complex assemblage, a collage of segments and significations and propositions, but also of lines of flight, asignifying elements, desiring machines that escape the order of definition and resist being overcoded that allow sense its free expression' (Bogard, 1998: 59).

The above quotation was used by Goodley (2007a) to emphasise the nature of the lives of parents of disabled children who resisted attempts for a static and singular subjectification of their lives. In my study the dominant machine would be that of rehabilitation discourses that have entered the lives of my participants. The emphasis on 'escaping the order of definition' and the refusal to be 'overcoded' seems to resonate with some of the experiences of the ABI survivors in my study. This is particularly evident in their refusal to adhere to the wishes of 'the rehabilitation machine' (eg. I won't get a job, I

won't strive for independence). However, at a time the participants seemed to be quite content to engage with the 'rehabilitation machine'. This is especially evident in early rehabilitation encounters when the participants expressed their fondness for certain rehabilitation professionals.

In the introduction to this thesis, I discussed how this thesis has been carried out as an exploration of identity (re)construction following ABI. This is a deliberate attempt to align with the aims of critical work in the field of disability studies. Shildrick (2012) observes that critical theory can play an important part in rethinking dominant discourses and taken for granted 'truths' in arenas such as neurological rehabilitation since it can encourage us to no longer explore *how* these interventions occur, but crucially to interrogate *the reasons for* such interventions. In exploring the experiences of ABI survivors, I have been able to disentangle some of the relevant issues in the (re)construction of identity following ABI (such as the recognition of the importance of interdependence) which can be used to demonstrate the reasons for some rehabilitation interventions. I now describe some more ways in which my study seems to align with this approach to researching disabled people's lives.

In a brief synopsis of the way in which a critical approach seems to be guiding the path of contemporary disability studies research Goodley (2013a) states:

> 'If (late) twentieth century disability studies were associated with establishing the factors that led to the structural, economic and cultural conditions of the exclusion of people with sensory, physical and cognitive impairments, then critical disability studies in the current century might be seen as a time of developing nuanced and sophisticated theoretical responses to these conditions' (Goodley 2013a: 69).

Furthermore, when writing in support of the attributes of critical work in disability studies, Shildrick (2012) states:

> 'My claim is not that the postmodernist enquiry of CDS [critical disability studies] could ever provide final answers, but that... the work of critique is to keep alive the very process in which questioning itself generates new potential' (Shildrick 2012: 30).

When these assertions are applied to this thesis, I have explored the experiences of my participants as they relate to their every-day activities. This enables me to look beyond the taken-for-granted assumed 'truths' regarding the lives of ABI survivors (such as the effects of impairment) and instead these experiences stimulate much thought regarding the reasons for (Shildrick 2012) and the assumptions upon which various rehabilitation interventions are based. For example considering Eric's experiences, it would appear that both the effects of impairment (the difficulty he finds in standing for long periods), and the way that ABI survivors feel they are viewed by others in society (his concern over the invisibility of his

impairment) both interact to make the completion of every-day activities such as catching a bus difficult. This has direct implications for the role of rehabilitation since the experiences of Eric suggest that the labelling process is as significant as impairment(s) in the (re)construction of his identity following ABI.

In exploring the identity (re)construction of the participants, I have opened up the process of rehabilitation to critical evaluation, Using a critical, social scientific framework to help me understand experiences of the participants I provide empirical data which may be used to underpin 'nuanced and sophisticated theoretical responses' (Shildrick 2012) to the inner workings of institutions (such as rehabilitation units). This is evident in the way that the participants recalled the importance of early interactions with rehabilitation professionals.

However, the advantages of the use of critical social scientific frameworks are not noted by all disability studies researchers. For example Barnes (2012) states:

> 'Whilst postmodernist accounts reaffirm the importance of the cultural in the process of disablement, they downplay the material reality of disabled people's lives' (Barnes 2012: 23).

By negotiating space for a questioning of the neurological rehabilitation process, whilst at the same time paying close attention to the daily details of the lives of people who have sustained ABI, in this thesis I have enabled a critique of rehabilitation, whilst also documenting some of the day-to-day activities of my participants. When these day-to-day activities are considered much is the learned about the identities of my participants. An example of this would be the way that participants (particularly Karl) appeared to be troubled by the way that long-term, and at times inaccurate prophecies on propensity for recovery were made. It has been stated that we are living in the time of complex identity politics where the ethics of care and debates around the significance of the body are guiding us towards (re)thinking the parameters upon which disability is judged (Goodley 2013a). By exploring the identity (re)construction of ABI survivors, my study adds to the existing literature regarding the identity of disabled people as such an exploration provides an ABI survivors' perspective on their identity (re)construction within the contemporary social world.

A critical analysis of the (re)construction of identity of ABI survivors can add to debates regarding ABI rehabilitation. It has been widely observed that the medical aspects of ABI and indeed (the medical aspects of) rehabilitation following ABI have been negotiated within existing literature (for example Bjorkdahl et al. 2006; Bowen et al. 2001). However, these have largely been short-term randomised

controlled clinical trials (RCT's) which focus upon medical aspects of rehabilitation, which sometimes exclude the evaluation of individual experience (Turner-Stokes 2008). In noting the importance of every-day life events following ABI and their contribution towards identity reconstruction following ABI, this study provides empirical data which enables a longer-term consideration of the lives of ABI survivors. Rather than excluding the evaluation of individual experience (Turner Stokes 2008), this study has represented such individual experience of living life following ABI.

Furthermore existing research on ABI has highlighted that there is an ever pressing need for a holistic approach to rehabilitation research which utilises 'a wide range of research designs in the analysis of evidence for effectiveness of rehabilitation' (Turner-Stokes 2008: 699). This study has provided empirical data through the use of qualitative methods which have represented the experiences of ABI survivors. In representing the perspective of the ABI survivor, this empirical data adds to existing data which can be used to analyse the effectiveness of rehabilitation.

It can be observed in literature which analyses ABI rehabilitation from a clinical perspective that many authors have commented on the absolute dominance of medical discourses in literature concerning brain injury (Gelech and Dejardins 2011; Medved and Brockmeir

2008; Mills 2011). Indeed, it has been noted that there is an overwhelming absence of the application of critical social science amongst health professions involved in neurological rehabilitation (Gibson and Teachman 2012). In engaging with a critical social scientific framework, I have sought to depart from medical discourses and attended to the unpredictable social factors within the lives of my participants. Throughout this thesis I have drawn attention to the way ABI and ABI rehabilitation is often conducted according to a framework which relies on medical 'facts'. In researching ABI from a social scientific perspective, I have sought to offer an alternative theorisation of ABI which highlights the (re)construction of identity of ABI survivors which is drawn from a careful analysis of the experiences of the participants. My analytical framework which highlights the 'rhizomatic' and 'nomadic' aspects of the identity of ABI survivors, has allowed me to represent the every-day experiences of the participants which highlights the way that various impairments have been integrated into the identities of the participants. The use of my analytical framework to analyse the experiences such as Sam's recollection of how being labelled 'brain injured' helped him secure housing has allowed me to draw attention to the way that some participants do not conceptualise the ABI solely in terms of the limitations their impairment(s) provide. Similarly the use of an analytical framework which highlights the 'rhizomatic' and 'nomadic' nature of identity has enabled me to recognise the role of other people (for example, friends) and objects (for example, walking

aids) in the (re)construction of identity following ABI. The use of a 'rhizomatic' and 'nomadic' analytical framework has also enabled me to consider the experiences of my participants as they relate to time. For example, the way that Rob recalled being told his left hand "will never recover to the way it was before (his) injuries" has had a long-lasting impact on the (re)construction of his identity. In analysing experiences such as this according to a framework which highlights the 'rhizomatic' and 'nomadic' features of identity, interactions between ABI survivors and rehabilitation professionals can be analysed in terms of their impact on identity (re)construction. Using my analytical framework also enabled me to highlight the fluid and unpredictable nature of the lives of some of the participants (for example in Sam's new-found interest in spending time with his family) where the recognition of the passing of time and getting older, may be as significant as the acquisition of impairment(s) in the (re)construction of identity following ABI.

The use of my critical, social scientific analytical framework suggests rather than focusing on how people who have had brain injuries are 'damaged', perhaps it would be useful for rehabilitation professionals to deconstruct their own practice in the search for how they could better adapt to the complexities that people who have sustained brain injuries embody (Medved and Brockmeir 2011; Mills 2011). For example, an appreciation of the way impairments are integrated into the life of an ABI survivor (such as the change in daily routine that

Wayne recalls) could be important in clinical interventions. To provide an example of the way this has been recently discussed in the rehabilitation literature, within the field of Psychology it has been noted that:

> '... as clinical professionals we need a better understanding of how people make sense of themselves, especially under extreme circumstances, before reaffirming or reconstructing a putatively damaged "self" in people of whom the only thing we know is that they have a damaged brain' (Medved and Brockmeir 2011: 471).

In this thesis I have (re)presented the experiences of fellow ABI survivors as they relate to the (re)construction of their identities. My study has been conducted as a move toward understanding the complexity of the identity (re)construction process following ABI. It has emerged that an engagement with activities that comprise identity (re)construction following ABI can inform the way researchers, practitioners and others frame the lives of ABI survivors rather than relying on traditional ways of conceptualising ABI that rely on medical descriptions of impairment(s).

In using a critical social scientific framework this research has sought to encourage a wider discussion of the multiplicity of interconnecting factors which make up the human person and in doing so encourage 'an awareness of the social, economic, and cultural processes which make up our lives' (Marks 1999: 187). After exploring the theoretical

tenets of my thesis I now move on to further discuss how this study has contributed to the methodological understanding of research.

Method/ological implications

I stated in the introduction chapter that due to the inherent links between the method and the methodology of research, I have considered them to overlap and mutually influence each other throughout this study. As such, it is appropriate to discuss some reflections on each one in turn. In the addition one of my research questions was to investigate how being an ABI survivor and working in an ABI support group has impacted on the research. Thus it seems appropriate that I carefully reflect on some of the ways I have influenced the project. However, before I turn to this I begin with some reflections on my method.

Method/ological implications I: Reflections on Method

The empirical data within this thesis has enabled me to capture the complexity of living life following ABI in a rich and complex way. As I introduced in an earlier chapter, no two brain injuries are ever the same, and impact on an individual's life in a variety of different ways.

The study involved the production and analysis of data gleaned from two semi-structured interviews with six ABI survivors. The data were

analysed thematically using Braun and Clarke's (2006) framework for thematic analysis. Within all forms of qualitative research that is investigative in nature it is important that the line of questioning is not rigidly predetermined and is centred on the experience of participants (DiCicco-Bloom and Crabtree 2006). In appreciating these concerns about remaining open to participant experiences, I feel that together with my methodological approach, taking time to plan interviews helped me strike a balance between asking relevant and precise questions and at the same time not condensing participant experiences. In addition to having personal knowledge of being an ABI survivor, engaging with literature detailing previous approaches to research aided my choice of an appropriate method.

With particular reference to the finer details of the interviews, I was keen to avoid the situation that Paterson and Scot- Findlay (2002) encountered in their pilot study where participants 'appeared tired, slurring their words and slumped in their chairs' (Paterson and Scott-Findlay 2002: 402). I believe I was successful and the accounts within this thesis provide vital glimpses into the unique nature of brain injury (Medved and Brockmeir 2008) as well as demonstrating how individuals respond to, and in many cases resist, dominant societal belief systems, such as the portrayal of brain injury as simply a medical phenomenon.

It is often noted that people who have sustained brain injury, may experience attention deficits (Lynch and Kosciulek 1995; Paterson and Scott-Findlay 2002). This results in interviewees becoming distracted and restless during the interview (Paterson and Scott-Findlay 2002). The issue of participant fatigue was also a factor in me deciding to conduct relatively short, multiple interviews. I decided that rather than carrying out one or two longer interviews, it may be more appropriate to carry at a series of shorter interviews. After engaging with the literature concerning carrying out interviews with ABI survivors I thought that perhaps an interview length of approximately 45 minutes would be appropriate. Largely due to the existence of literature warning against conducting lengthy interviews together with the experimental nature of this thesis I thought it would be wise to carry out a pilot interview. Following the success of the pilot interview 45 minutes seemed to be a suitable time-frame for the interviews, as I thought I may struggle to elicit sufficient information in less than 45 minutes, and at the same time I was keen to avoid participant fatigue. In making the interviews relatively short, I hopefully avoided participants becoming distracted and restless and at the same time gave myself enough time to elicit the relevant experiences of my participants. People who have sustained a brain injury are often stated to be a difficult 'group' to elicit thoughtful responses from (Paterson and Scott-Findlay 2002; Sherry 2006). For example, Paterson and Scott-Findlay (2002) report that asking imprecise questions in their study such as "what concerns do you

have at the moment?" was unlikely to provoke an extensive response. The way that this question is highlighted as being a question that was not considered relevant for use in interviews carried out with those who have sustained a brain injury in particular, makes me feel uneasy. The reason for this is that I feel this is not a particularly relevant nor thought-provoking question for use in any research interview, not simply in interviews carried out with those who have sustained a brain injury. This assertion seems to provide another example of the impairment and deficit focused way in which ABI survivors are portrayed in terms of what they may lack rather than what they have. Within my research I spent a great deal of time devising appropriate questions and following this carried out a pilot interview. For example, in designing the questions I considered it my responsibility to be aware of some common difficulties that are faced after brain injury. The way ABI survivors fatigue quickly is a feature of much of this literature. In addition this was something that was also highlighted during my first pilot interview. As a result of the impact of fatigue, I had to be aware of eliciting the relevant experiences of the participants in relatively short periods of time, which led to my decision to carry more than one interview with each participant. Being informed by the relevant literature together with carrying out a pilot phase, enabled me to focus on the experiences of my participants rather than highlighting the difficulties of the interview process. The use of my analytical framework which highlights the 'rhizomatic' and 'nomadic' attributes of the identity of the participants also provided

me with the analytical tools to focus on the possibilities rather than the difficulties of carrying out interviews with the participants.

Instead of viewing the potential responses of my participants as problematic to the research process, I feel it was part of my role to foresee some of these challenges and devise strategies to overcome them (Kvale 1996; Mason 2002). In choosing to enact the interviews in a quiet space, away from the hustle and bustle of the support group I feel I was able to ensure that the participants (and myself) were able to concentrate fully on the task in hand which ultimately resulted in the data being far more rich and descriptive in nature. Choosing to conduct the interviews in a quiet space also negated some issues of confidentiality.

As well as the impairment centred nature of much disability research it has also been observed that studies exploring brain injury often employ the perspective of health professionals, rather than that of the recipient of rehabilitation services (Gill 2012). Rather than provide yet another study which ignores the perspectives of the recipients of rehabilitation services, this study sought to find an effective way of extrapolating this knowledge whilst being mindful of potential challenges.

In direct opposition to the theorisation of disabled people's lives which serves to highlight impairments in the lives of ABI survivors, there are also exists research which attempts to transfer all focus on to the particulars of the disabling society. As I highlighted in the method/ology chapter much of this research is enacted under the social model of disability.

The social model of disability has been criticised as being overly concerned with structure (Sherry 2006). Whilst not wishing to down play the revolutionary way of the theorising disabled people's lives that the social model provoked, the structuralist nature of the Social Model of disability and its exhaustive focus upon disabling barriers, denies agency among disabled people (Sherry 2006). As a disabled person, I absolutely agree that disabling practices and barriers that exist in society should be highlighted. However, throughout this thesis I have highlighted the way research with disabled people, does not necessarily need to focus on impairment based factors or indeed disabling barriers in isolation. This study has suggested that research with disabled people can be presented as investigation of the lived experience of disability and impairment. In using a critical, social scientific framework to analyse the (re)construction of identity of ABI survivors which highlights the 'rhizomatic' and 'nomadic' nature of the identity of ABI survivors, this thesis has discussed impairment based issues (Rob's inability to swim at international level) as well as wider social issues (the psycho-emotional disablism Eric faced on the

bus) in the lives of the participants. I have also been able to note experiences of the participants which emphasised the possibilities their impairments represented (Sam being a happy person nine times out of ten). Within this research I have sought to highlight the experiences of my participants which appear to deviate from an exhaustive focus on the melancholic, barrier focussed way of theorising disabled people's lives, and at the same time have not returned to a singular discussion of impairments.

Rather than focusing upon the negative aspects of the lives of the participants, investigating the (re)construction of identity after ABI using a critical, social scientific framework has highlighted the way that although the commonality between participants is that they and indeed I were all ABI survivors; ABI does not necessarily seem to be a defining factor in determining experiences after ABI. This seems to contradict the suggestion that disabled people should be drawn together. Rather, the lives of my participants were unique and I have found huge differences between participants.

In evaluating the method/ological aspects of my study, my role as a researcher is something that I wish to critique in a thorough way. I feel being an ABI survivor was particularly important in ensuring that I provide adequate answers to my research questions, thus strongly guiding my methodological approach. For example, I was personally

aware of the fatigue that brain injury survivors endure. Thus finding a way to minimise such fatigue was clearly an important consideration in the planning phase of my research. A careful reflection on my role as the researcher, and how the choices that I made (i.e. to become a volunteer prior to data collection) is necessary as there is no doubt that this helped to shape the data I collected. In addition an analysis of my own impact on the research formed the third of my research questions. I believe it is important to thoroughly consider the way we as researchers effect our research rather than solely being concerned with participant performance. The in-depth consideration of my own performance in the interviews provides an example of where I felt as the researcher I had to take responsibility for the study. Consequently I now turn to a reflection of my role in the research.

Method/ological implications II: My role in the research

In the literature relating to qualitative research it has been noted that the positioning of the researcher and their thoughts on how knowledge is produced is pivotal (Goodley et al. 2004; Letherby 2002, 2003; Letherby et al. 2012). However, this has been said to be a particularly crucial component of any qualitative research within the healthcare arena (Coben and Crabtree 2008). It has been stated that any qualitative research should highlight this importance and thus thoroughly evaluate the role of the researcher during data collection (Cohen and Crabtree 2008).

Following these assertions, the acceptance of the importance of my position in the research, led to the formation of my third research question.

- *In what ways may being an ABI survivor and volunteering in an ABI support group impact on the research?*

It is now roughly 10 years since I sustained a traumatic brain injury. Having time and space to reflect on the period of my life since the injury has afforded me the opportunity to reflexively consider the aspects of my identity (re)construction since I sustained an ABI. As I have already discussed, reflexive and/or long- term experiences are often overlooked in research concerning those who have sustained ABI (Lorenz 2010; Sherry 2006). This has played a key role in the production of research into ABI being solely focused upon negative changes (Gelech and Dejardins 2011). Having experience of ABI has undoubtedly shaped my research and shaped the type of questions that I asked the participants.

The way that I am also a brain injury survivor dictates that for obvious reasons I would not want to dwell upon the negative changes that are associated with living life after ABI. In considering this, I recognise that my own experiences may well have also limited as well as increased the 'legitimacy' of my study. Thus, this thesis presents

the perfect example of how the identity of the researcher is deeply embedded in the research that is produced. In this regard I follow Goodley et al. (2004) when they state:

> 'Ethnographic research can be embraced as a methodology that aims to *look again at the cultures we may feel we already know so well.* In this sense, ethnography is about turning a critical eye onto practices, dynamics, policies and meaning making within familiar cultures. It means turning social contexts into research contexts: the latter is associated inevitably with the participant turned-researcher examining the social context anew through the perspective of a critical enquirer.' (Goodley et al. 2004: 57 emphasis in original)

Following the lessons I have learnt throughout this study, I would agree that social contexts can be turned into research contexts. Furthermore in including my own experiences, I also highlight the fluidity of the identities of disabled people. Consequently, the inclusion of my own experiences in conjunction with those of my participants demonstrates how we as ABI survivors are able to navigate through different social spaces and environments (Prain 1997; Piper 2004; Sikes 2006; Thompson and Gunter 2011), the realisation of which is crucial in applying this work. Throughout this study I have considered how my own identity has affected and been effected by the research. An example of this is provided in an earlier chapter where I discuss the way that I considered seemingly mundane aspects of the research process such as how to dress during volunteer sessions.

Although my experiences of ABI and ABI rehabilitation provided an advantage in certain ways, for example in the way that participants seemed to believe that I could empathise with their experiences, I feel that my familiarity with ABI was not a sole ingredient for the success of the study. Throughout the research I remained mindful of the insights of contemporary social theory which emphasises the unique nature of lives. I have found that such social theory has aligned with the lives of my participants in many ways not least in an appreciation of the multiplicity of competing discourses which help to shape lives. Consideration of the way that I have found that the identities of the participants are made up of many different facets, dictates that being an ABI survivor is just one of these facets. The way that this study has highlighted the dynamic and fluid nature of identity after ABI reinforces this. Therefore, my similarity to the participants is found in just one of the many complicated features of identity that comprise the (re)construction of identity following ABI.

Concerning the times where I felt my position as a fellow ABI survivor may have provided difficulty to overcome in their study, the prevalence of discourses which highlight the medically 'damaged' nature of ABI survivors, dictates that many people (ABI survivors included) through no fault of their own have preconceived ideas regarding the competence of ABI survivors. I was however, thoroughly prepared for this as familiarising myself with literature regarding ABI survivors, and perhaps more importantly, drawing

upon my own experiences of identity (re)construction following ABI, I was able to realise the dominance of impairment-based preconceptions of ABI survivors, and recognise this as a potential obstacle in my study. I addressed this concern by making sure that I was thoroughly prepared for the interviews by thoughtfully considering and piloting the interview questions, the location for the interviews, the duration of the interviews and so on.

I feel the project benefited hugely from the way I joined an ABI support group and formed equal and reciprocal relationships with participants prior to data collection. I created these reciprocal relationships largely due to my personal experience of identity (re)construction following ABI together with my reading of literature concerning identity that suggests that identity is constructed of a plethora of divergent and fluid strands, meaning that the sharing of a single aspect of identity does not render any person the same.

In summary during the entire research project I was aware that research conducted with disabled participants has been criticised for tending to focus upon the impairment(s) of individual participants rather than critically examining the method/ological approach itself (Goodley 1996; Mills 2011; Paterson and Scott-Findlay 2002; Sherry 2006). Although I do not want to solely focus upon the challenges that come with interviewing people who have sustained ABI, it would

be naive of me to ignore these altogether. Thus, it is important that I highlight the way that I have found working alongside brain injury survivors to be reasonably challenging.

Rather than focus on the negatives of researching with ABI survivors, I want to highlight the way that with effective planning, many of these challenges have not simply been obstacles that need to be overcome to ensure the success of the study. Many of these challenges have provided opportunities in which to be reflective upon my practice as a researcher. This has given me an opportunity to give great consideration to the method/ological intricacies of the study including my appearance, my professionalism and so on.

In thoroughly deconstructing my approach to the research, I attempted to follow research which suggests that researchers should enact a thorough interrogation of their identity. Indeed I attempted to create a situation where I was 'reading me into the problem' (Mills 2011: 21) and analysing the way I responded to the complexities of carrying out interviews with ABI survivors, rather than concentrating on the difficulties that my participants may bring. I think it is useful concentrating on my own performance rather than highlighting *their* impairments and the difficulties *they* bring to the interview process. Providing a different perspective on the lives of ABI survivors

necessitates that there are indeed several limitations to this project. I discuss some of these below.

Limitations

My study was based on the accounts of a small (n=6) number of participants. The small number of participants could be said to mean that these insights are not applicable to the lives of other ABI survivors. However, I do not believe this limits their application to others who may have sustained ABI. I rely upon the numerous assertions, both clinical (Fleminger and Ponsford 2005; Collicutt Mcgrath 2007) and sociological (Sherry 2006; Lorenz 2010) that have highlighted the way that no two brain injuries, or two responses to ABI are ever the same. Such assertions cast significant doubt upon the way the activities of one person who has sustained ABI can be used as a predictor/explanatory tool for the life of another. In gathering subjective accounts, I wholly recognise the myriad ways that different people respond to any given situation.

Added to the heterogeneity of individual people, these variations also occur due to the range of interconnecting influences that shape our experiences. Gelech and Dejardin (2011) observed in their research with ABI survivors '... the self depends heavily on relationships with the others and our links to the social world for its construction'

(Gelech and Dejardins 2011: 66). Therefore, it is impossible to completely standardise the type of responses I elicit. To do so would be to deny the individuality of my participants and would have been to the detriment of my study. I chose to limit my study of the experiences of identity (re)construction after ABI to those of young men (aged 18-30 years at the time of the ABI and 25-33 years at the time of the interviews). This decision was made as an attempt to ensure a degree of consistency of experience and a small enough range to enable me to draw some firm conclusions.

In critically analysing my project, it is important that I refer back to the questions which have driven the study. In exploring the way that my study may contribute to discussions of disability identity and rehabilitation after ABI, rather than suggesting one single 'correct' way to live following brain injury, my study simply represents how different people have lived their lives following brain injury. Much of the empirical data within this thesis suggests a view of the (re)construction of identity after ABI which celebrates the uncertainty, ambiguity and at times, confusing nature of the phenomenon. Furthermore I have not felt it appropriate to in any way judge or critique the way that any of the participants have lived life after their brain injury. Rather, it is my intention to (re)present the experiences of my participants. These experiences may at times interweave but are unique to each person. These findings reinforce the suitability of my decision to keep my sample fairly small and the

findings of this study suggest that considering the unpredictable nature and varied nature of these experiences.

Practical Implications

This study provides a significant contribution to knowledge in the study of the identity of ABI survivors and disabled people. As well as this, the study may also have some broader (practical) applications. These include implications for both practitioners who are involved in the rehabilitation of ABI survivors, and there are also implications for everyone who may come into contact with ABI survivors during their daily lives.

This study has explored the (re)construction of identity following ABI. In demonstrating the fluidity and changing nature of identity after ABI, this thesis has important implications for the way in which the identity of ABI survivors is viewed. This study has suggested that the identity (re)construction process following ABI is a complicated process which includes issues such as family networks, friendship circles, employment, education and learning and so on.

More specifically, the thesis has explored the notions of dependence, independence and interdependence in the lives of my participants. This serves as an important reminder as to the way that identity is

constructed. The empirical data contained in this thesis encourages further debate about whether lives should be considered in isolation. It may be the case that rehabilitation services could gain much insight from engaging with wider patient support networks search as family, friends and so on. The data within this chapter also highlights the way that rehabilitation is a process that relies heavily upon taken for granted, assumed 'truths'. A close engagement with the multi-faceted nature of the identities of ABI survivors may aid rehabilitation professionals who work with ABI survivors to centre their practice around individual ABI survivors and their sources of support, rather than focusing on common impairments following ABI.

The importance of time and the future in the (re)construction of identity following ABI is also explored. Perhaps it may be useful for rehabilitation frameworks to adopt a more forward-looking approach which seeks to highlight the possibilities of the lives of ABI survivors rather than always classifying them by time-limited conceptions of what they may lack and identifying them through their impairments.

The study explored the every-day details of the lives of the participants. Closely engaging with the day-to-day experiences of ABI survivors has led me to conclude that these experiences provide the opportunity to consider the uniqueness of each ABI survivor. This offers an alternative to discourses which suggest ABI is a

homogenous, stable, phenomenon, with definite outcomes. I hope this thesis encourages rehabilitation practitioners and researchers to carry out a more sophisticated investigation of the lives of ABI survivors and what may be important to each person. Additionally, this study and engagement with this thesis may well help family members of people who have sustained ABI. Similarly, this thesis would also appear to be of interest to ABI survivors themselves particularly those who may be early on in the rehabilitation process.

In terms of approaches to the rehabilitation of ABI survivors, this thesis without doubt has implications for service providers. This is particularly evident in the data I have presented which relate to goal setting within neurological rehabilitation. The relevance of both short and long-term goal setting is rather important. Within clinical settings, further care may need be taken to emphasise the uncertain nature of long-term goal setting within neurological rehabilitation. This thesis has sought to raise the question of whether this is this achievable within current frameworks.

Given that the majority of research concerning medical conditions such as ABI is carried out according to quantitative paradigms, my research also contributes to the body of literature concerning ABI and ABI rehabilitation in that it is conducted according to qualitative paradigms. Due to the way that my research is different to many of

the studies concerning ABI and ABI rehabilitation I have been keen to highlight where the findings could be useful for future research and practice. Much research concerning ABI and rehabilitation following ABI has focused upon the medicalisation of these injuries with an overbearing focus on individual impairments and the deficits that they bring (Gelech and Dejardins 2011; Medved and Brockmeir 2008; Mills 2011).

This study also adds to the body of literature which explores how the identity of the researcher impacts on research design and data collection. In this sense, this study will also be of great use to researchers in any social scientific discipline who wish to enable a greater understanding of researcher identity in social research.

Overall, this thesis has explored the lives of ABI survivors. A critical, social scientific approach has been used which investigates important questions in the lives of ABI survivors. For example, this thesis has grappled with common issues relating to ABI such as how power is used in situations of dependence. In this way, this thesis is of relevance to rehabilitation professionals involved in the rehabilitation of ABI survivors in a range of settings.

Directions for Future Study

This thesis indicates that future research concerning the lives of disabled people may well benefit from transferring the focus from impairment based factors onto the every-day activities of the research participants. Certainly in my study, consideration of the diverse determinants of identity such as family interaction, social networks, hobbies and so on has enabled a greater understanding of the way that the impairment(s) have impacted upon individual people's lives on a long-term basis.

Regarding future research into ABI, this thesis has focused on the long-term complexities of ABI survivors' lives. At present there is a particular paucity of research which seeks to explore the lives of ABI survivors on long-term basis. As such a key finding from this thesis is that there is much to be gained from engaging with the long-term activities of ABI survivors.

The integration of critical social theory into studies regarding ABI and ABI rehabilitation enables the theorisation of the lives of ABI survivors to be understood more fully. Consequently, I suggest that the use of a critical analytical framework enables the views of ABI survivors to be used to inform and improve the rehabilitation process after ABI. Furthermore considering debates regarding the complex

and ever changing nature of neurological rehabilitation after ABI, it would seem sensible to suggest that future research could encompass many different paradigmatic standpoints to achieve an overall impression of the efficacy of the neurological rehabilitation process. This may well encourage the enactment of qualitative studies regarding neurological rehabilitation alongside clinically based RCT's. A situation where both qualitative and quantitative approaches to research are considered equally important in research concerning ABI would encourage a longer-term consideration of ABI especially in terms of the impact it has on identity.

I believe that future research into ABI, as well as disability as a whole, could benefit from an acceptance of the way that being an ABI survivor, or indeed having similar impairments, does not necessarily mean that any two people lead similar lives. The fluidity of identity that this thesis has suggested indicates that identity is made up of many diverse and interconnected facets, and future research and practice would benefit from recognising this. Hierarchical, power laden relationships within research and practice could be replaced by partnerships where commonalities are found between disabled and nondisabled people.

Final reflections

Overall this thesis has explored the identity (re)construction of ABI survivors. Within this thesis I have found that the identity of ABI survivors is a complicated, ever-changing and dynamic notion. The participants talked about the different factors that comprise their identity. They talked about how issues such as family, friends, interests, education and learning, employment and so on played a key role in determining their identities. Similarly some participants also highlighted the importance of impairment(s) in their identity (re)construction. Therefore this thesis has highlighted the many facets of identity that are determined on an individual and unpredictable basis.

One of the more important lessons that I have learnt from the study is that the subject (ABI) has multiple meanings depending on the perspective taken on the subject. This thesis has highlighted the effect that ABI has in the (re)construction of the identity of ABI survivors. In addition, the engagement with the lives of ABI survivors has enabled the enactment of a critical review of the rehabilitation process. Given the paucity of research that explores the lives of ABI survivors it is my belief that in engaging with the bodies and minds of people who have negotiated/are still negotiating the rehabilitation process, many of the solutions to the provision of optimal rehabilitation services can be found.

This exploration of the lives of ABI survivors has highlighted life as a fluid entity as participants' identities have evolved in a mobile and dynamic fashion. This thesis suggests that future rehabilitation programs should recognise this fluidity. Furthermore this thesis suggests that rehabilitation should create a space for critical interrogation of its workings whereby reliance upon brute 'facts' is replaced by a nuanced and unique approach to each individual ABI survivor. An approach which seeks to engage with the experiences of ABI survivors will further enable an understanding of the complexity of identity.

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Appendix 1

Participant Information Sheet

'Navigating the Complexities of acquired brain Injury'
Jonathan Harvey

Firstly I would like to thank you very much for taking time to read through this information sheet. I hope you will find it useful. If you would like any more information please do not hesitate to contact me.

I am conducting some research, which will focus upon the lives of people how have sustained an acquired brain injuries. I am particularly interested in this subject as I too sustained an acquired brain injury roughly 10 years ago. I have found that there is lot of research into the effects of short-term neurological rehabilitation, but the long-term realities of living life after acquired brain injury seem to be less clear. I think this research will prove to be very important, as it will remind people of what it is like to live after an acquired brain injury and may (hopefully) have some effect on future services.

I would like to carry out two or three interviews with you, each lasting about 45 minutes. Although I would like to hear about your experiences, you are absolutely welcome to bring a family member or friend

to the interviews. In these interviews I would like to ask questions about the details of your life since your brain injury. The interviews will be based around what you want to talk about as there are no fixed topics. You are the experts on your rehabilitation. I would just like you to share some of that expertise in my research.

The interviews will be transcribed by a professional transcription service, and your name will be removed from the transcription, ensuring that your confidentiality will at all times be protected. I will be using the transcription of the interviews as part of my qualification. I will be beginning the interviews in November and although the best time to tell me you no longer want to participate is then, you retain the right to withdraw from the study (and have all recordings/transcriptions destroyed) at any time. Some of the material from the interviews may be published. I also intend including our discussions in conference presentations. I will write a short summary of my findings and provide a copy for you which you can read in your own time.
Finally, if you have any questions about the study, please do not hesitate to contact me at the address below.

Thanks for your time.

Yours,

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